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Promotion and protection of human rights: human rights questions, including alternative approaches for improving the effective enjoyment of human rights and fundamental freedoms

Rights of persons with disabilities

Note by the Secretary-General

The Secretary-General has the honour to transmit to the General Assembly the report of the Special Rapporteur on the rights of persons with disabilities, Catalina Devandas-Aguilar, submitted in accordance with Human Rights Council resolution 35/6.

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Report of the Special Rapporteur on the rights of persons with disabilities

Summary

In the report, the Special Rapporteur on the rights of persons with disabilities examines the challenges experienced by persons with disabilities in the enjoyment of their right to the highest attainable standard of health, and provides guidance to States on how to promote health-care services that are inclusive of, and accessible to, persons with disabilities.

I. Introduction

1. The present report underscores the various challenges faced by persons with disabilities to the enjoyment of their right to the highest attainable standard of health, and provides guidance to States on how to promote human rights-based health-care services that are inclusive and accessible. The international human rights standards presented in the report build on previous recommendations by the United Nations human rights mechanisms, including treaty bodies and special procedures.

2. In preparing her report, the Special Rapporteur analysed 116 responses to a questionnaire sent to Member States, national human rights institutions and civil society organizations, including organizations representing persons with disabilities.[1] She also organized an expert consultation with representatives of United Nations agencies, organizations of persons with disabilities and academics.

II. Understanding the health of persons with disabilities

3. Health is central to well-being and human happiness. It enables individuals to have a good life and reach their full potential. When people do not have access to health care, including medical and rehabilitation services, they may be unable to attend school, access livelihood opportunities or participate in society. Health is essential to economic growth, as healthy populations study more, are more productive, save more and live longer.[2] Early access to health and rehabilitation services ensures better health outcomes and reduces the costs incurred by health and social care systems associated with poor health. Health goes beyond formal health-care systems. Factors such as safe and affordable housing, transportation, education and employment also have an impact on the health of individuals and communities. Accordingly, health is both an outcome of and a path to achieving sustainable development (see A/71/304).

4. Persons with disabilities have the same health needs as everybody else, including the need for health promotion, preventive care, diagnosis, treatment and rehabilitation. They may also have additional specific health needs resulting from their impairments and other underlying determinants of health, such as poverty, discrimination, violence and social exclusion. While some impairments inevitably progress over time, poor physical and social environments can aggravate primary conditions or exacerbate secondary consequences of primary conditions.

5. Owing to high levels of poverty, discrimination, violence and social exclusion, as well as significant barriers in access to health-care services, persons with disabilities are at higher risk of developing ill-health than the general population and, therefore, more likely to require and use health-care services. For example, they are at higher risk of unintentional injury; developing secondary, co-morbid and age-related conditions; being exposed to violence; and premature death.[3] Likewise, they are in greater need of health-related habilitation and rehabilitation services, which are key to maintain a good health state, live independently, be economically productive, and live meaningful lives. Some persons with disabilities might need more access to specialist health-care services, in addition to primary health-care services.

[1] See www.ohchr.org/EN/Issues/Disability/SRDisabilities/Pages/StandardOHealth.aspx.

[2] See D. Bloom and D. Canning, *Population Health and Economic Growth* (Commission on Growth and Development, 2008). Available at https://siteresources.worldbank.org/EXTPREMNET/Resources/489960-1338997241035/Growth_Commission_Working_Paper_24_Population_Health_Economic_Growth.pdf.

[3] World Health Organization (WHO) and World Bank, *World Report on Disability* (2011), pp. 53–60.

6. Persons with disabilities can lead active, productive, long and healthy lives. Having an impairment does not equate to being unhealthy. Health is a dynamic state of well-being resulting from a combination of an individual's potentials, life's demands and social and environmental determinants.[4] Regardless of the impairment or health condition, persons with disabilities can enjoy healthy lives by identifying and realizing their aspirations, satisfying their needs and changing or coping with the environment.[5] Moreover, it is important to acknowledge that the notion of impairment varies throughout history, cultures and societies, reflecting the values and norms of a specific time and place.[6] Similarly, many persons with disabilities do not see their bodily and functional diversity as actual impairments, but as positive and normal traits of their identity or as perceived impairments.

7. Historically, persons with disabilities have been seen merely as "patients", and their views held less value than those of so-called "experts", particularly medical professionals. Under the medical model of disability, persons with disabilities were not recognized as rights-holders but "reduced" to their impairments.[7] As their disability was perceived only as a medical problem, societal responses focused on "fixing" and "curing" them, disregarding their own will and preferences. Since the 1960s, however, the disability rights movement has challenged such medical models and highlighted the negative role of barriers and oppression in the lives of persons with disabilities. Consequently, disability is nowadays understood as a social construct resulting from the interaction between persons with actual or perceived impairments and attitudinal and environmental barriers. Departing from the practice of pity and treatment, persons with disabilities should now be recognized as equal members of a diverse humanity.

8. The issue of prevention of impairments deserves clarification. States often present policy and budget commitments related to primary prevention policies as investments in the rights of persons with disabilities. While public health campaigns to prevent sickness and impairments in the general population are an important component of a State's public health policy, they should not be considered as part of the efforts to promote the rights of persons with disabilities. From a human rights perspective, States must ensure that persons with disabilities have access, on an equal basis with others, to health promotion and prevention services, including prevention of further impairments. Furthermore, States must guarantee that policies and programmes on health promotion and prevention do not stigmatize persons with disabilities, as this has a direct negative impact on their inclusion and participation in society.

[4] J. Bircher and E.G. Hahn, "Understanding the nature of health: new perspectives for medicine and public health. Improved wellbeing at lower costs", *F1000Research* 5:167 (2016). Available at https://f1000research.com/articles/5-167/v1.

[5] The Ottawa Charter for Health Promotion, adopted at the First International Conference on Health Promotion, held in Ottawa on 21 November 1986.

[6] B. Ingstad and S. R. Whyte (eds.), *Disability and Culture* (University of California Press, 1995).

[7] Committee on the Rights of Persons with Disabilities, general comment No. 6 (2018) (CRPD/C/GC/6), para. 8.

III. The right to health of persons with disabilities

9. The right to health is recognized in various international and regional human rights instruments.[8] It encompasses both freedoms and entitlements.[9] Freedoms include the right to non-discrimination, the right to make decisions affecting one's health and bodily integrity, the right to free and informed consent, the right to be free from non-consensual medical treatment and experimentation and the right to be free from torture or cruel, inhuman or degrading treatment or punishment. Entitlements include the right to essential primary health care and the right to access essential medicines. The right to health extends to the underlying determinants of health, such as access to safe drinking water; adequate sanitation; adequate food, nutrition and housing; healthy occupational and environmental conditions; and access to health-related education and information.[10]

10. States are obliged to respect, protect and fulfil the right to health. Accordingly, States must refrain from interfering directly or indirectly with a person's health; take measures to prevent third parties from interfering with it; and take positive measures to enable and assist individuals and communities to enjoy this right. Furthermore, States must ensure that health-care goods, services and facilities are available in adequate quantity (availability); are financially, geographically and physically accessible, including accessible information and communication, without discrimination (accessibility); are respectful of medical ethics, culturally appropriate and sensitive to gender and life-cycle requirements (acceptability); and scientifically and medically appropriate and of good quality (quality). The right to health also demands the participation of the population in all health-related decision-making.[11]

11. Persons with disabilities are protected by the same general framework of the right to health as everybody else. However, the international human rights system paid little attention to their health needs until the adoption of the Convention on the Rights of Persons with Disabilities.[12] In fact, that framework allowed for restrictions on their enjoyment of different elements of the right to health in exceptional circumstances. For example, the Principles for the Protection of Persons with Mental Illness and the Improvement of Mental Health Care established a lower standard of protection against human rights violations in health-care settings.

12. The Convention on the Rights of Persons with Disabilities[13] supersedes those previous standards. It moves away from medical and paternalistic approaches to disability towards a human rights-based approach, which considers persons with disabilities as rights-holders, rather than as mere recipients of protection, rehabilitation or welfare. Disability is no longer seen as a medical problem but as a

[8] See Universal Declaration on Human Rights (art. 25.1), International Covenant on Economic, Social and Cultural Rights (art. 12), International Convention on the Elimination of All Forms of Racial Discrimination (art. 5 (e) (iv)), Convention on the Elimination of All Forms of Discrimination against Women (arts. 11.1 (f) and 12), Convention on the Rights of the Child (art. 24), International Convention on the Protection of the Rights of All Migrant Workers and Members of Their Families (arts. 28, 43.1 (e), and 45.1 (c)), Convention on the Rights of Persons with Disabilities (art. 25), European Social Charter (Revised) (art. 11), Additional Protocol to the American Convention on Human Rights in the Area of Economic, Social and Cultural Rights (art. 10) and African Charter on Human and Peoples' Rights (art. 16).

[9] Committee on Economic, Social and Cultural Rights, general comment No. 14 (2000) (E/C.12/2000/4), para. 8.

[10] Ibid., para. 11.

[11] Ibid.

[12] G. Quinn and T. Degener, "Human rights and disability: the current use and future potential of United Nations human rights instruments in the context of disability" (Geneva, OHCHR, 2002). Available at www.ohchr.org/Documents/Publications/HRDisabilityen.pdf.

[13] United Nations, *Treaty Series*, vol. 2515, No. 44910.

social construct. The Convention highlights the need to remove all societal structures, barriers and practices that limit the full and equal enjoyment of the right to the highest attainable standard of health by all persons with disabilities.

13. Many provisions of the Convention relate to the right to health, or to the underlying determinants of health. Article 25 of the Convention reaffirms the right of all persons with disabilities to the enjoyment of the highest attainable standard of health without discrimination. This includes all the elements of the right to health framework, including, inter alia, freedoms, entitlements, participation, monitoring and accountability. Article 25 also provides a non-exhaustive list of standards and obligations that States must guarantee in the implementation of the right to health, including access to sexual and reproductive health services; access to population-based public health programmes; the provision of services as close as possible to communities, including in rural areas; the provision of disability-specific health services, including prevention of further impairments; the provision to persons with disabilities of health care of the same quality as that provided to others, including on the basis of free and informed consent; the training of health professionals and the promulgation of ethical standards for public and private health care; equal access to health insurance and life insurance; and prohibition of the denial of health care or food and fluids on the basis of disability.

14. Article 25 (d) of the Convention merits particular attention. It refers to the right to free and informed consent to medical treatment and experimentation, including the right to refuse treatment, which is widely recognized in international human rights law.[14] Despite being a core element of the right to health and the right to be free from torture and ill-treatment, it is often denied to persons with disabilities. For example, articles 6 and 7 of the Convention on Human Rights and Biomedicine of the Council of Europe, adopted in 1997, allow exceptions to the right of persons with disabilities to be free from non-consensual medical hospitalization and experimentation. Similarly, certain United Nations treaty bodies and special procedures have justified the use of coercion against persons with disabilities in health care, including involuntary treatment and hospitalization, solitary confinement, the use of restraints and forced sterilization on the basis of notions of "medical necessity" and "dangerousness" (see, for example, CCPR/C/GC/35 and A/HRC/22/53). These standards and jurisprudence are contrary to the Convention on the Rights of Persons with Disabilities, which prohibits all forms of coercion on the basis of actual or perceived impairment, even if additional factors or criteria are used to justify them.

15. Furthermore, article 25 (d) of the Convention establishes the obligation to "require health professionals to provide care of the same quality to persons with disabilities as to others, including on the basis of free and informed consent"; an obligation that is reinforced by the universal recognition of legal capacity of personal with disabilities (art. 12) and the absolute ban of deprivation of liberty on the basis of impairment, including non-consensual hospitalizations (art. 14). The Committee on the Rights of Persons with Disabilities has stressed that States parties have an obligation not to allow substitute decision-makers (e.g., guardians) to provide consent on behalf of persons with disabilities.[15] Instead, supported decision-making regimes should be made available and health and medical personnel should take measures to ensure that supporters are respectful of the individual's will and preferences and do

[14] International Covenant on Civil and Political Rights (art. 7), Universal Declaration on Bioethics and Human Rights (arts. 5 and 6) and Convention on Human Rights and Biomedicine (art. 5). The right to free and informed consent has also been interpreted to be part of the right to security of the person, the right to freedom from torture and cruel, inhuman, and degrading treatment or punishment, the right to privacy and the right to the highest attainable standard of health.

[15] Committee on the Rights of Persons with Disabilities, general comment No. 1 (2014) (CRPD/C/GC/1), para. 41.

not substitute or have undue influence over the decisions of persons with disabilities.[16] In cases where significant efforts have been made and it is not possible to obtain an individual's free and informed consent or to ascertain their will and preferences, including through the provision of support and accommodations, the standard of "best interpretation of the will and preference" should be applied as a last resort.[17]

16. Other provisions of the Convention complement article 25. For example, article 5 prohibits all forms of discrimination, including in health care; article 9 requires the accessibility of all medical facilities, transportation, information, communications and services; article 10 reaffirms the right to life of persons with disabilities; articles 15 and 17 recognize the right to be free from torture or cruel, inhuman or degrading treatment or punishment and the right to personal integrity, including freedom from non-consensual medical treatment; article 19 provides for the right to live independently and be included in the community, which precludes segregation and institutionalization in health-care settings; article 22 recognizes the right to privacy, including privacy of health-related information; article 23 provides for the right of persons with disabilities to access reproductive and family planning education and to retain their fertility and decide on the number and spacing of their children, which precludes forced sterilization; article 21 addresses access to information, which combats health illiteracy; and article 28 addresses the rights to adequate standard of living and social protection, which cover social determinants of health.

17. Article 26 of the Convention complements the obligation to guarantee health services needed by persons with disabilities specifically because of their impairment. It requires States to implement comprehensive habilitation and rehabilitation services and programmes,[18] including in the area of health, to enable persons with disabilities to attain and maintain maximum independence, full physical, mental, social and vocational ability, and full inclusion and participation in all aspects of life. These services and programmes should begin at the earliest possible stage; be based on a multidisciplinary assessment; support participation and inclusion; be voluntary; and be available as close as possible to people's communities. Furthermore, article 26 requires States to train professionals and staff working in habilitation and rehabilitation and to promote the availability, knowledge and use of assistive devices and technologies.

18. The right to health contains both obligations of immediate effect and an obligation of progressive realization. The former include core obligations such as non-discrimination; freedom from non-consensual medical treatment and experimentation; access to food, basic shelter, housing and sanitation and safe and potable water; and access to essential primary health care and medicines.[19] The latter imposes an obligation on States to move as expeditiously and effectively as possible, making full use of their available resources, including those made available through international cooperation, towards the full realization of the right to health.[20] Such steps must be deliberate, concrete and targeted,[21] and include the adoption of

[16] Ibid.

[17] Ibid., para. 21.

[18] Habilitation and rehabilitation describe a broad range of responses to enable persons with disabilities to attain and maintain maximum independence, full physical, mental, social and vocational ability and full inclusion and participation in all aspects of life. Habilitation refers to services targeting those who acquire impairments congenitally or early in life, whereas rehabilitation refers to services for those who acquire an impairment later in life.

[19] Committee on Economic, Social and Cultural Rights, general comment No. 14 (2000) (E/C.12/2000/4), para. 43.

[20] Ibid., paras. 31 and 32.

[21] Ibid., para. 30.

indicators and benchmarks to properly monitor progress over time. In the view of the Special Rapporteur, access to essential habilitation and rehabilitation, to essential assistive devices and to essential health services needed by persons with disabilities owing to their impairment should be considered as core obligations that are not subject to progressive realization.

19. States have an obligation to protect persons with disabilities against violations of their right to health within their territory and/or jurisdiction by third parties. The Convention specifically requests States parties to take all appropriate measures to eliminate discrimination on the basis of disability by any person, organization or private enterprise (art. 4.1 (e)); and to ensure that private entities offering facilities and services open or provided to the public take into account all aspects of accessibility (art. 9.2 (b)). States should prevent, address and redress human rights abuses committed by non-State actors in the private sector as outlined in the Guiding Principles on Business and Human Rights (A/HRC/17/31, annex).

20. The commitment to leave no one behind demands that all persons with disabilities can enjoy the full range of opportunities created by the 2030 Agenda for Sustainable Development (General Assembly resolution 70/1), including the various health-related goals, which represent an opportunity to advance the right to health of persons with disabilities. The Convention on the Rights of Persons with Disabilities offers normative guidance for the implementation of the Sustainable Development Goals from a human rights-based perspective. Disaggregated data, as called for in Goal 17, are needed to measure whether persons with disabilities are being left behind in access to health care.

IV. Challenges and concerns

21. The Special Rapporteur has identified three main challenges associated with the enjoyment of the right to health by persons with disabilities: (a) health and health-care inequalities; (b) barriers to accessing health-care services; and (c) specific human rights violations in health-care settings.

A. Health and health-care inequalities

22. Persons with disabilities experience significant health and health-care inequalities. Secondary and co-morbid conditions are common among persons with disabilities and include chronic health conditions such as high blood pressure, cardiovascular diseases and diabetes. Although some of these outcomes are impairment-related, inequities in access to health care, health literacy and economic resources are at the root of the vulnerability to many of these conditions and/or contribute to aggravating them. For example, studies show that on average persons with intellectual disabilities die 15 to 20 years earlier than the general population owing, to a significant extent, to neglect, poor treatment and failure to undertake routine screening, health promotion and prevention activities.[22] Similarly, the life expectancy of adults with psychosocial disabilities is about 20 to 25 years shorter owing to multiple factors, including somatic disease associated with antipsychotic medication.[23]

[22] Health Quality Improvement Partnership, *The Learning Disabilities Mortality Review*, annual report 2017.

[23] S. Saha, D. Chant and J. McGrath, "A systematic review of mortality in schizophrenia: is the differential mortality gap worsening over time?", *Archives of General Psychiatry*, vol. 64, No. 10 (2007), pp. 1123–1131.

23. Furthermore, persons with disabilities are significantly more likely to need health-care services than persons without disabilities, while also being more likely to report not receiving them.[24] For example, a study found that persons with disabilities had thrice the level of unmet health-care needs than those without disabilities.[25] Evidence also suggests that persons with disabilities are disadvantaged in accessing primary care, which perpetuates a cycle of poorer health outcomes for them. Children with disabilities often do not receive basic treatment for common childhood illnesses, which may become life threatening if left untreated.[26] There is a false assumption that persons with disabilities always require specialized services, when the majority of their health needs can be met by primary care.

24. Access to health-related habilitation and rehabilitation services is limited among persons with disabilities. While different categories of people require rehabilitation services, coverage is generally low across the diversity of persons with disabilities.[27] This includes access to physical therapy, speech and language therapy and psychosocial rehabilitation. Coverage is particularly limited in low- and middle-income countries, where in some settings only 3 to 5 per cent of persons with disabilities benefit from those services.[28] Moreover, evidence indicates that in many low- and middle-income countries only 5 to 15 per cent of persons with disabilities requiring assistive devices and technologies have access to them.[29]

25. Persons with disabilities face significant challenges to accessing specialist health-care services, which are essential for many groups. For instance, a significant number of newborns with congenital impairments such as spina bifida and hydrocephalus die before one month of age owing to the absence of specialized treatment.[30] Likewise, the lack of accurate diagnosis and effective treatments for the majority of rare diseases represents a challenge worldwide.[31]

26. Generally, persons with disabilities are not targeted by strategies for health promotion and disease prevention. Children with disabilities are often excluded from immunization programmes, even in countries where overall immunization rates have increased dramatically.[32] Several studies have shown that women with disabilities have limited access to cancer screening services.[33] Persons with albinism lack access to adequate sun protection. Deaf persons experience significant knowledge gaps in preventive health. Similarly, efforts to promote healthy behaviours, such as regular

[24] WHO and World Bank, *World Report on Disability* (2011), pp. 60–62.

[25] M. A. McColl, A. Jarzynowska and S. E. D. Shortt, "Unmet health care needs of people with disabilities: population level evidence", *Disability and Society*, vol. 25, No. 2 (2010), pp. 205–218.

[26] WHO and United Nations Children's Fund (UNICEF), "Early childhood development and disability: a discussion paper" (2012), p. 17.

[27] T. Shakespeare, T. Bright and H. Kuper, "Access to health for persons with disabilities", discussion paper commissioned by the Special rapporteur on the rights of persons with disabilities (2018), pp. 21–26. Available at http://disabilitycentre.lshtm.ac.uk/resources/.

[28] Ibid, p. 24.

[29] WHO, Assistive technology fact sheet (18 May 2018), www.who.int/en/news-room/fact-sheets/detail/assistive-technology.

[30] WHO, Congenital anomalies fact sheet (7 September 2016), www.who.int/news-room/fact-sheets/detail/congenital-anomalies.

[31] European Commission, *Rare diseases — a major unmet medical need* (2017), p. 9.

[32] UNICEF, "Disability prevention efforts and disability rights: finding common ground on immunization efforts", working paper, available at www.unicef.org/disabilities/files/UNICEF_Immunization_and_Disability_Paper_FINAL.pdf.

[33] J. Angus, L. Seto, N. Barry et al., "Access to cancer screening for women with mobility disabilities", *Journal of Cancer Education*, vol. 27, No. 1 (March 2012), pp. 75–82; K. Eaters and A. Cotton, "Barriers to breast cancer screening in Australia: experiences of women with physical disabilities", *Journal of Clinical Nursing*, vol. 24, Nos. 3 and 4 (March 2012), pp. 563–72.

exercise and good diet, generally are not accessible and place little emphasis on addressing the needs of persons with disabilities.[34]

27. While persons with disabilities are as sexually active as everyone else, they have limited access to sexual and reproductive health-care services. Several studies have found that they have lower levels of access to quality services than persons without disabilities, including lower access to sexuality education and knowledge on sexual and reproductive health and rights.[35] Young people with disabilities, for example, generally show lower levels of knowledge concerning HIV transmission and prevention.[36] Women and girls with disabilities also report that their needs and expectations are not met by antenatal and gynaecological services.[37]

28. Persons with disabilities experience great inequalities in oral health and access to dental health care. Most dental care needs of persons with disabilities, as those of the general population, are not complex and can be dealt with in primary care and community settings.[38] However, they experience greater levels of oral disease than the rest of the population, as well as higher levels of unmet needs for dental care.[39] Particularly high levels of untreated dental disease have been found in persons with disabilities with high support needs and those in institutional settings.[40]

29. Often persons with disabilities do not receive the mental health care they may need and seek. As raised by the Special Rapporteur on the right to health, there is an alarming "global burden of obstacles" that hinders the implementation of the right to mental health, including the dominance of a "biomedical model", power asymmetries and the biased use of evidence in mental health (see A/HRC/35/21). This approach to mental health has contributed to the stigma, exclusion, neglect, coercion and abuse of persons with disabilities, particularly those with psychosocial and intellectual disabilities, dementia and autism, and has further limited the policy responses to provide mental health care and psychosocial support to those who seek it. For example, public expenditures on mental health services are mostly directed to in-patient care, especially psychiatric hospitals and residential institutions, while community-based and non-coercive psychosocial services are barely funded.[41]

30. The underlying determinants of health are also of concern. Persons with disabilities are more likely to experience poverty and social exclusion, which increases both the likelihood of ill-health and of facing barriers to accessing health care. Persons with disabilities are also at higher risk of experiencing violence (see A/70/297). Adults with disabilities run twice the risk of violence as persons without disabilities, rising to six times the risk in the case of adults with psychosocial disabilities.[42] Children with disabilities are six times as likely as other children to experience violence and abuse.[43] Children with psychosocial or intellectual disabilities have a higher prevalence and risk of violence than children with other

[34] J. H. Rimmer, "Health promotion for people with disabilities: the emerging paradigm shift from disability prevention to prevention of secondary conditions", *Physical Therapy*, vol. 79, No. 5 (1 May 1999), pp. 495–502.

[35] S. H. Braathen, P. Rohleder and G. Azalde, *Sexual and reproductive health and rights of girls with disabilities: a review of the literature* (SINTEF, 2017), pp. 13–15. Available from www.sintef.no.

[36] Ibid., pp. 13–14.

[37] Ibid., p. 16.

[38] World Dental Federation, "Oral health and dental care of people with disabilities", policy statement adopted by the FDI General Assembly, Poznań, Poland, September 2016.

[39] D. Faulks and others, "The value of education in special care dentistry as a means of reducing inequalities in oral health", *European Journal of Dental Education*, vol. 16 (2012), pp. 195–201.

[40] Ibid.

[41] WHO, *Mental Health Atlas 2014* (Geneva, 2015), p. 31.

[42] T. Shakespeare, T. Bright and H. Kuper, "Access to health for persons with disabilities" (note 27 above), p. 8.

[43] Ibid.

disabilities. Furthermore, many health-related problems common among children with disabilities can be attributable to restricted access to basic underlying determinants of health, like safe drinking water, bed nets and nutrient-rich foods.[44]

B. Barriers to accessing health-care services

31. Stigma and stereotypes are major barriers to accessing health care. Although evidence proves otherwise, misconceptions about the health of persons with disabilities have led to the assumption that their needs cannot be addressed by primary health services, or that they are not good candidates for health promotion and disease prevention. Stigma and stereotypes also lead to negative and hostile attitudes among service providers. For example, they play a significant role in limiting the sexual and reproductive health and rights of girls and young women with disabilities (see A/72/133). Furthermore, shame and stigma associated with disability prevent persons with disabilities and their families from seeking medical attention or rehabilitation.

32. There is a need to rethink and review international health-related tools and standards that can contribute to further stigma and pathologization of disability. Diagnostic tools and classification instruments such as the International Classification of Diseases and the Diagnostic and Statistical Manual of Mental Disorders can reinforce public stigma and cause people to avoid seeking health care for fear of being labelled.[45] Similarly, health metrics such as the quality-adjusted life year and the disability-adjusted life year, which are widely used to estimate longevity and health-related well-being and to guide the allocation of resources, are controversial for the ethical implications of the disability weights and their impact on policymaking.[46]

33. Health-related habilitation and rehabilitation services are scarce for persons with disabilities. Evidence suggests that the demand for rehabilitation is much higher than what these services can provide.[47] Where rehabilitation is available, efforts have been concentrated disproportionately in hospital-centred rather than locally available services. Physical therapies are also more commonly available than other interventions, such as speech and language therapy. The shortage of professionals who deliver rehabilitation services (e.g., physiotherapists, occupational therapists, speech and language therapists, optometrists, audiologists or general practitioners working on rehabilitation), and their concentration in urban areas, also represent significant barriers for those seeking rehabilitation, particularly in low- and middle-income countries.[48] Specialist health services and professionals are usually scarce in low- and middle-income countries.

34. Persons with disabilities also face restrictions in accessing health care owing to the lack of physical accessibility of buildings, equipment and services. Furthermore, the distance to and from health-care facilities in rural and remote areas constitutes a significant barrier to persons with disabilities owing to poverty, the absence of accessible and affordable transport and the lack of family and community support. Other common accessibility barriers include the lack of information in accessible

[44] UNICEF, "Disability prevention efforts and disability rights" (note 32 above), p. 3.

[45] D. Ben-Zeev, M. A. Young and P. W. Corrigan, "DSM-V and the stigma of mental illness", Journal of Mental Health, vol. 19, No. 4 (2010), pp. 318–27.

[46] D. A. Pettitt and others, "The limitations of QALY: a literature review", *Journal of Stem Cell Research and Therapy*, vol. 6, No. 4 (2016), p. 4; R. Parks, "The rise, critique and persistence of the DALY in global health", *The Journal of Global Health* (1 April 2014), available at www.ghjournal.org/the-rise-critique-and-persistence-of-the-daly-in-global-health/.

[47] WHO, "The need to scale up rehabilitation", available at www.who.int/disabilities/care/NeedToScaleUpRehab.pdf?ua=1.

[48] WHO and World Bank, *World Report on Disability* (2011), p. 66.

formats (e.g., in Braille or plain language); communication barriers (e.g., the lack of sign language interpretation or the absence of training for service providers in communicating with children and adults with intellectual disabilities); relatives and caregivers acting as gatekeepers to information and services; and the isolation of persons with disabilities in institutions, camps, family homes or group homes (see A/72/133).

35. Financial barriers to accessing health care are significant among persons with disabilities. While their health-care costs are often higher, they are less likely to be employed and on average are poorer than those without disabilities. Evidence shows that 51 to 53 per cent of persons with disabilities cannot afford health care, compared with 32 to 33 per cent of persons without disabilities.[49] Persons with disabilities are also 50 per cent more likely to experience catastrophic health expenditure (out-of-pocket spending exceeding a household's ability to pay), which pushes them into poverty.[50] The high pricing of medicines and the lack of or limited access to generic medicines is also a significant barrier for those who need to take medication for prolonged time periods.

36. Discrimination in health insurance is another major barrier to accessing health care. Coverage rates are frequently low because insurance companies often refuse to offer health-care insurance to persons with disabilities due to pre-existing conditions. Discrimination may also occur in the way that insurance plans are designed, limiting the benefits or coverage that a person with disabilities can receive or increasing disproportionally the cost of the insurance premium. Such practices violate the Convention on the Rights of Persons with Disabilities.

37. Acceptability and quality of health-care services are also a challenge. Health services and programmes are not generally adapted to the diversity of persons with disabilities, including gender, life-cycle and intercultural requirements. Indeed, many children with disabilities do not transition from paediatric to adult health care owing to the unavailability of specialists or the reluctance of general practitioners to treat persons with disabilities. Additionally, services do not always respect confidentiality and the privacy of persons with disabilities. For example, deaf people often face breaches of their privacy because family members may be needed to act as their interpreters.[51] Furthermore, in many countries, access to health care and rehabilitation services is conditioned upon obtaining a disability certificate, which constitutes an arbitrary requirement.

C. Specific human rights violations in health-care settings

38. In many countries, persons with disabilities are denied treatment on the basis of their disability. While justifications range from lack of accessibility to insufficient health insurance coverage, the assumption that persons with disabilities have less value or enjoy less quality of life lies at the root of many practices. Afflictions and medical symptoms of persons with disabilities are often seen as part of their impairment, resulting in lack of treatment. Even more troublesome, persons with disabilities are often deemed as unworthy of treatment; many children and adults with disabilities are not offered or are denied treatment, including life-saving and life-extending treatments, as such interventions are considered pointless and inefficient. For example, a study found that many health-care providers do not support standard emergency interventions, such as a thoracotomy, for patients with fresh spinal cord

[49] Ibid.

[50] Ibid., p. 67.

[51] Y. Bat-Chava, D. Martin, and J. G. Kosciw, "Barriers to HIV/AIDS knowledge and prevention among deaf and hard of hearing people", *AIDS Care*, vol. 17, No. 5 (2005), pp. 623–634.

injury.[52] Failure to ensure access to life-saving treatment and medication for the relief of pain and suffering threatens the rights to life, health and freedom against cruel, inhuman and degrading treatment.

39. Denial of free and informed consent is a widespread violation of the right to health of persons with disabilities. Standard informed consent processes generally rely on written forms, which are inaccessible to blind persons and those who need interpretation or communication support. Most national legislations, particularly mental health laws, provide for the involuntary hospitalization and treatment of persons with disabilities on the grounds of their actual or perceived impairment, by itself or in conjunction with other factors like "medical necessity" and "dangerousness". In many countries, guardians and caregivers are allowed to provide consent to treatment on behalf of a person with disabilities, including experimental procedures. There is also an increase of mandatory outpatient treatment, which not only increases involuntary interventions but also allows for other forms of abuse such as illegal curfews and prohibitions.[53] Rates of involuntary hospitalization and treatment are exceptionally elevated in high-income countries, with numbers rapidly increasing in several European countries.[54] In this context, the introduction of new psychotropic drugs with a digital ingestion tracking system ("digital pills") is of great concern owing to their potential use for coercive treatment. It must be stressed that coercive practices have not only social and psychological effects but also a negative impact on physical health.

40. Persons with disabilities, especially girls and women, face serious human rights violations in the exercise of their sexual and reproductive health and rights. They are generally prevented from taking autonomous decisions with regard to their reproductive and sexual health and are regularly exposed to violence, abuse and harmful practices, including forced contraception, forced abortion and forced sterilization (see A/72/133). Evidence indicates that the sterilization of women and girls with intellectual and psychosocial disabilities continues to be prevalent.[55] Those who conceive run the risk of having their children taken away by the State or by their families.[56] Having a guardian or being placed in an institution increases the risk of being subjected to any of these practices.

41. There are a growing number of treatments and interventions whose effectiveness is uncertain or deemed controversial. These include, for example, electroconvulsive therapy; psychosurgery; experimental mercury detoxification treatments, harsh behavioural modification regimes and packing for autistic children; conductive education for children with cerebral palsy; and limb-lengthening for children with restricted growth.[57] Many of these interventions are invasive, painful and irreversible, and therefore may amount to torture or ill-treatment if applied involuntarily. In the case of children, these practices also contradict the principle of respect for the

[52] K. A. Gerhart and others, "Quality of life following spinal cord injury: knowledge and attitudes of emergency care providers", *Annals of Emergency Medicine*, vol. 23, No. 4 (1994), pp. 807–812.

[53] A. Molodynsky, J. Rugkåsa, and T. Burns, *Coercion in Community Mental Health Care International Perspectives* (Oxford University Press, 2016).

[54] H. J. Salize and H. Dressing, "Epidemiology of involuntary placement of mentally ill people across the European Union", *British Journal of Psychiatry*, vol. 184, No. 2 (February 2004), pp. 163–168; United Kingdom Department of Health and Social Care, "The independent review of the Mental Health Act", interim report, May 2018.

[55] L. Servais, R. Leach, D. Jacques and J. P. Roussaux, "Sterilisation of intellectually disabled women", *European Psychiatry*, vol. 19, No. 7 (2004), pp. 428–432; L. Lennerhed, "Sterilisation on eugenic grounds in Europe in the 1930s: news in 1997 but why?", *Reproductive Health Matters*, vol. 5, No. 10 (1997), pp. 156–161.

[56] T. Shakespeare, T. Bright and H. Kuper, "Access to health for persons with disabilities" (note 27 above), p. 31.

[57] Ibid, p. 10.

evolving capacities of children with disabilities and their right to preserve their identities.

42. Exploitation, violence and abuse against persons with disabilities within health-care settings are also frequent. Seclusion and restraints, including chemical restraints, are regularly used in many mental health services. These practices have no therapeutic objective and are frequently a consequence of the lack of support for people experiencing an emotional crisis and severe distress (see A/HRC/37/56). They are also used as a punishment to enforce compliance to treatment and medication. Likewise, overmedication of autistic persons, persons with psychosocial disabilities and older persons with disabilities is a widespread practice that can cause sedation, injury, cognitive or behavioural changes and death. Like all those placed in segregated settings, persons with disabilities are also at high risk of physical and sexual abuse and exploitation in places such as psychiatric institutions, nursing homes and residential treatment facilities for children.

D. Multiple and intersectional forms of discrimination

43. Persons with disabilities are a heterogeneous group with a wide range of impairments and identity traits such as race, colour, sex, sexual orientation, gender identity, language, religion, national, ethnic, indigenous or social origin and age. The interplay of these traits produces further health and health-care inequalities and barriers. For example, communication barriers are particularly high for migrants, refugees and asylum seekers with disabilities, and financial barriers are especially problematic for certain groups, such as Roma and indigenous persons with disabilities.[58]

44. Women with disabilities have consistently less access to health-care services and programmes than women without disabilities and men with disabilities.[59] They also experience worse health care and preventive care. Likewise, they are more likely to be subjected to violence, abuse and neglect and to experience human rights violations in the exercise of their sexual and reproductive health and rights. Women with severe impairments have higher chances of facing unmet needs and human rights violations in health-care settings.

45. Children and older persons with disabilities also report high levels of unmet health needs. A significant number of them are placed in institutions, considerably reducing their chances to receive proper nutrition and medical attention and increasing their risk of developing secondary conditions.[60] They are also at a particularly high risk of receiving treatment without their informed consent. In no case can the access to health-care of persons with disabilities be conditioned on their placement in residential institutions.

46. Furthermore, in recent years the number of children diagnosed with autism, attention deficit hyperactivity disorder and other conditions has grown exponentially, prompting a rapid increase of the prescription of stimulants and other psychotropic

[58] European Union Agency for Fundamental Rights (FRA), *Inequalities and multiple discrimination in access to and quality of healthcare* (2013), pp. 47–51.

[59] D. L. Smith, "Disparities in health care access for women with disabilities in the United States from the 2006 National Health Interview Survey", *Disability and Health Journal*, vol. 1, No. 2 (2008), pp. 79–88; D. Sakellariou and E. S. Rotarou, "Access to healthcare for men and women with disabilities in the UK: secondary analysis of cross-sectional data", *BMJ Open*, vol. 7, No. 8 (2017).

[60] K. Maclean, "The impact of institutionalization on child development", *Development and Psychopathology*, vol. 15, No. 4 (2003), pp. 853–884; F. D. Wolinsky and others, "The risk of nursing home placement and subsequent death among older adults", *Journal of Gerontology*, vol. 47, No. 4 (1992), pp. 173–182.

medications. These practices are generally the result of outdated understandings of disability and the lack of appropriate support. The Special Rapporteur stresses that pathologization and medicalization of the behaviour of children with disabilities represent an unacceptable practice that contradicts the principle of respect for the difference and acceptance of persons with disabilities as part of human diversity.

47. Persons with disabilities deprived of their liberty or in refugee camps face significant challenges in accessing health care owing to the lack of accessible facilities and communication support. The lack of access to medical attention in urgent cases and for those who require specialized treatment or surgery is particularly problematic.

V. Implementing the right to health of persons with disabilities

48. States can take a number of steps to improve the realization of the right to health of persons with disabilities, including reviewing their legal and policy frameworks; taking concrete measures in the areas of universal health coverage, accessibility, non-discrimination and participation; and mobilizing resources for the implementation of the relevant measures.

A. Legal framework

49. States must establish an enabling legislative and regulatory framework for the right to health of persons with disabilities. Laws that protect the health of the population should be reviewed in the light of the international framework for the right to health and the rights-based approach to disability. These provide that health-care goods, services and facilities should be made available, accessible, affordable, acceptable and be of good quality for persons with disabilities. Provisions that exclude or restrict access of persons with disabilities to health-care services, including sexual and reproductive health services, should be amended to facilitate universal and equitable access.

50. States must immediately repeal all discriminatory legislation that allows the hospitalization and treatment of persons with disabilities without their free and informed consent, and/or when decided by a third party, including guardians, family members and health professionals. States should instead ensure that advance planning and other forms of supported decision-making are available to those who may need them. Furthermore, States should consider allowing children to consent to certain medical treatments and interventions without the permission of a parent, caregiver or guardian, such as HIV testing and sexual and reproductive health services,[61] and consider adopting protocols to regulate the informed consent of children with disabilities to all surgical and other invasive procedures. Legislation must provide for effective remedies for persons with disabilities whose right to health has been violated, including adequate, effective and prompt redress and reparation for harm suffered, as well as judicial and administrative sanctions on perpetrators.

B. Policy framework

51. States must mainstream the rights and needs of persons with disabilities in both primary and specialist health-care policies and programmes. Access to primary care is essential to identify and address the general health requirements of persons with disabilities, but also to respond to their additional specific health needs, either directly

[61] Committee on the Rights of the Child, general comment No. 15 (2013) (CRC/C/GC/15), para. 31.

or through referral to specialist services. Excessive reliance on specialist care can prevent primary care involvement, lead to unnecessary diagnosis and treatment and make the health services more expensive. Therefore, secondary and tertiary health-care services should support and work in close partnership with primary care providers to respond to the health needs of persons with disabilities within their communities. Health promotion activities must be inclusive of persons with disabilities and address the particular health conditions they face, including their underlying determinants of health. Early identification and intervention strategies are also required to facilitate timely access to health-care services and to minimize and prevent further impairments. It is important to ensure these do not contribute to further discrimination and exclusion from mainstream services, such as education.[62]

52. States should establish a policy framework to organize, strengthen and extend comprehensive health-related habilitation and rehabilitation services and programmes for persons with disabilities. Efforts should include improving integration of health-related habilitation and rehabilitation in primary health care; building comprehensive service delivery models; developing a multidisciplinary rehabilitation workforce; and ensuring that rehabilitation is included within health-care budgets.[63] The policy framework should also ensure that persons with disabilities have access to accessible, adequate and affordable assistive devices and technologies.[64] While community-based rehabilitation can be effective in improving the health and quality of life of persons with disabilities, these interventions are usually restricted in their geographical coverage, limited in scope and unsustainable.[65] Ensuring access to health-related habilitation and rehabilitation services, as well as assistive devices and technologies, is a State obligation and responsibility that cannot be handed over to non-profit organizations and charities.

53. States must ensure that health care is provided as close as possible to the communities where persons with disabilities live, including rural and remote areas. Delivery of services at or close to home can improve access to health care. States need to ensure that their rural development strategies include measures to promote access to quality health care for persons with disabilities, including community-based strategies and outreach services (e.g. mobile clinics, health caravans, telemedicine and phone-based strategies). States should also consider adopting interventions aimed at improving the demand for health-care services among persons with disabilities themselves (e.g., text message reminders, peer health promoters and home visits).

C. Universal health coverage

54. Achieving universal health coverage is central to the Sustainable Development Goals. The goal of universal health coverage requires that all people and communities receive the essential health services they need, without being exposed to financial hardship. Goal 3 includes an explicit commitment to "achieve universal health coverage, including financial risk protection, access to quality essential health-care services and access to safe, effective, quality and affordable essential medicines and vaccines for all " (target 3.8) and to "ensure universal access to sexual and

[62] WHO and UNICEF, "Early childhood development and disability: a discussion paper", (2012) p. 22.

[63] WHO, "Rehabilitation 2030: a call for action", meeting report, 2017, available at www.who.int/disabilities/care/Rehab2030MeetingReport2.pdf?ua=1.

[64] For further guidance on how to ensure access to assistive devices and technologies, see A/71/314.

[65] V. Iemmi and others, "Community-based rehabilitation for people with disabilities in low- and middle-income countries: a systematic review", Campbell Systematic Reviews, 2015. Available from https://campbellcollaboration.org/.

reproductive health-care services, including for family planning, information and education, and the integration of reproductive health into national strategies and programmes" (target 3.7). Health-related indicators of Goal 3 also acknowledge a wide range of services, including health promotion, prevention, treatment, rehabilitation and palliation, and the need to measure the coverage of essential health services among the general and the most disadvantaged populations, such as persons with disabilities.

55. Against this background, universal health coverage can be an important instrument to increase the access of persons with disabilities to health care. However, to make it happen, States need to take into account persons with disabilities when considering expanding the population covered by health-care services; the services included in the benefits package; and the proportion of cost covered. In particular, States need to ensure that the implementation of universal health coverage — from packages of essential health services to health financing reforms — includes the full range of health-care services that persons with disabilities may need, including health-related habilitation and rehabilitation, assistive devices and technologies[66] and essential medicines. For example, in Sierra Leone, the Disability Act of 2011 allows for persons with disabilities to access free medical services in all public health institutions. Discussions on universal health coverage should take into account increasingly available health-care technology and treatments that have the potential to increase life expectancy and the quality of life of persons with disabilities (e.g., surgeries for children with spina bifida or cardiac surgeries for children with Down syndrome).

D. Accessibility

56. States must ensure the full accessibility of health-care services and programmes. All public and private health-care facilities and services must take into account all aspects of accessibility for persons with disabilities, including the accessibility of infrastructure, equipment and information and communications. Accessible transport must be also guaranteed, as otherwise persons with disabilities cannot reach health-care services or facilities.

57. All information and communications pertaining to the provision of health care, including electronic services and emergency services, should be accessible to persons with disabilities, including through sign language, Braille, accessible electronic formats, alternative script, easy-to-read formats and augmentative and alternative modes, means and formats of communication.[67] All public health campaigns must be also accessible and inclusive of persons with disabilities. For instance, in Nigeria, in order to address accessibility concerns, sign language interpreters have been posted in hospitals to focus on the sexual and reproductive health-care needs of women with disabilities within the Federal Capital Territory.

E. Non-discrimination

58. States have an obligation to provide health-care to persons with disabilities without discrimination. States must therefore eliminate discrimination against persons with disabilities in law, policy and practice, and prohibit all forms of discrimination in the provision of health care. For instance, States should refrain from

[66] States should develop a list of essential assistive products according to their national needs and available resources on the basis of the WHO priority assistive products list (see A/71/314).

[67] Committee on the Rights of Persons with Disabilities, general comment No. 2 (2014) (CRPD/C/GC/2), para. 40.

providing health-care services predominantly in institutional and residential settings. In addition, States need to take measures to provide reasonable accommodation to persons with disabilities so that they can access and enjoy these services and facilities on an equal basis with others. While accessibility is subject to progressive realization, States have an immediate obligation to provide reasonable accommodation so that persons with disabilities can access health-care right away.

59. States must prohibit and combat discrimination against persons with disabilities in the provision of health insurance. Denial of health insurance to persons on the basis of their disability must be legally banned. States should also consider adopting regulations to ensure that insurance plans and premiums are fixed in a fair and reasonable manner. In Mexico, for example, the Supreme Court of Justice has ruled that insurance companies cannot discriminate against persons with disabilities in the provision of health insurance, and should adopt policies and plans for their inclusion.

60. Health systems must respond to the needs of the diversity of persons with disabilities. States need to pay attention to the existing layers of identities within the disability community in order to adequately address the inequalities and intersectional discrimination experienced by persons with disabilities. States should consider developing and implementing policies and practices targeting the most marginalized groups of persons with disabilities (e.g., persons with multiple or severe impairments, rare diseases or deaf-blindness) in order to accelerate or achieve de facto equality in access to health care.

F. Participation

61. States must consult and actively involve persons with disabilities, including children with disabilities, in the implementation of health-care services. Persons with disabilities know best which barriers they face in their own contexts and how they affect their lives. Their participation ensures that States' health policies and programmes are devised on the basis of their needs and preferences, which can result in greater efficiency and a more equitable use of resources. For example, in Bosnia and Herzegovina, cooperation between the government and organizations of persons with disabilities led to the creation of accessibility standards for health-care institutions. The Special Rapporteur has developed a thematic study on the right of persons with disabilities to participate in decision-making that provides specific guidance on how to meet this obligation (see A/HRC/31/62).

62. States should be aware that the views of persons with disabilities may conflict with those of health professionals, as the latter are usually trained to act in the best interest of the patient, and many hold paternalistic and medicalized views of disability. Persons with disabilities should be recognized as the main interlocutors when it comes to their own rights and States should always give priority to their opinions in matters affecting them. Similarly, umbrella organizations of persons with disabilities might have different views from specific groups, thus the importance of consulting and engaging directly with all stakeholders. States should also ensure that the diversity of persons with disabilities is represented and consulted in decision-making processes related to the right to health.

G. Accountability

63. Accountability is crucial for ensuring that health-care services are inclusive and respectful of the rights of persons with disabilities. National health strategies and plans should have clear lines of accountability, with indicators and benchmarks that facilitate the monitoring of the implementation of the right to health of persons with

disabilities. Quality disaggregated data are also needed to identify gaps and outcomes in health care. The governmental focal points and coordination mechanisms for the implementation of the Convention on the Rights of Persons with Disabilities, as required by its article 33 (1), should facilitate and support the implementation of health strategies and plans from the perspective of a rights-based approach. To prevent the occurrence of all forms of exploitation, violence and abuse in the provision of health care, States must ensure the independent monitoring of all health facilities and programmes, as well as the establishment of appropriate and effective safeguards.

64. States must provide for enforcement mechanisms to guarantee the effective implementation of the right to health of persons with disabilities. Any person or group of persons with disabilities that has been the victim of a violation of the right to health should have access to effective judicial or other appropriate remedies.[68] These remedies should include adequate reparations, including restitution, compensation, satisfaction and guarantees of non-repetition, as appropriate. National human rights institutions and independent mechanisms to promote, protect and monitor the implementation of the Convention should be mandated to carry out inquiries and investigations (art. 33 (2)), as well as provide assistance to persons with disabilities in accessing legal remedies. Consumer protection agencies should conduct inquiries and investigations on discrimination against persons with disabilities in the provision of health insurance and life insurance.

H. Resource mobilization

65. States have an obligation to take immediate steps, making full use of their available resources, including those made available through international cooperation, to ensure that persons with disabilities have access to health care. In many countries, health-related habilitation and rehabilitation services and programmes, including the provision of assistive devices and technologies, are underfunded. Consequently, many persons with disabilities do not have access at all to those services or, at most, depend on non-profit organizations or private charities to access them. Government health planning and budgeting need to incorporate the specific health services needed by persons with disabilities, as well as the particular needs of persons with disabilities across all budget lines. Social protection systems can also help to address the additional costs that persons with disabilities face in accessing health care, and to facilitate support services for those who may need it (see A/70/297).

66. In considering the allocation of resources, States should pay attention to their core obligations in relation to the right to health, particularly ensuring essential primary health care for all persons with disabilities. Ensuring financial protection for persons with disabilities should be a key consideration in decision-making for universal health coverage. States should not adopt retrogressive measures that affect the right to health of persons with disabilities, as well as refrain from funding practices contrary to the human rights-based approach to disability (e.g., institutionalization or coercive health interventions).

I. Awareness-raising

67. States Parties must adopt immediate, effective and appropriate measures to raise awareness throughout society regarding persons with disabilities and their health needs from a rights-based approach. Persons with disabilities should not be seen as

[68] Committee on Economic, Social and Cultural Rights, general comment No. 14 (2000) (E/C.12/2000/4), para. 59.

ill or as patients, but rather as rights-holders in the same way as every member of society. States must also foster respect for the right to health of persons with disabilities through the sensitization and training of health-care professionals and staff. Training should also address the intersecting forms of discrimination that affect persons with disabilities in the enjoyment of the right to health. Medical and health professional schools should review their curricula to ensure that the education they offer adequately reflects the health-care needs and rights of persons with disabilities. Furthermore, suitable qualified persons with disabilities should be supported in their efforts to be trained as health professionals themselves.

68. Health literacy strategies targeting persons with disabilities should be implemented, including through the provision of health-related information in a variety of formats, so that persons with disabilities can be in a position to obtain, process and understand basic health information and services needed to make appropriate health decisions. In Ecuador, for example, the Ministry of Public Health has developed a manual on sexual and reproductive health for persons with disabilities, which establishes guidelines for service providers on how to ensure the access of persons with disabilities to information and services.

69. Awareness-raising campaigns and training programmes to promote the right to health of persons with disabilities must adopt a human rights-based approach to disability. Public fundraising campaigns in support of habilitation and rehabilitation services, such as telethons, reinforce a charity approach and a pervasive pathologizing view of disability. Similarly, public delivery events of assistive devices and technologies, such as wheelchairs and other mobility devices, are contrary to respect for the inherent dignity of persons with disabilities and reinforce a charity approach to disability.

J. International cooperation

70. International, South-South and triangular cooperation play a crucial role in supporting national efforts to implement the Sustainable Development Goals. States and international donors need to ensure that all international cooperation in the area of health, including international development programmes, is inclusive of, and accessible by, persons with disabilities. International cooperation in the area of health must also be consistent with the human rights of persons with disabilities and provided in a sustainable and culturally appropriate manner. International organizations, non-profit organizations, charities and other organizations operating in national contexts should refrain from implementing projects contrary to the human rights-based approach to disability (see A/HRC/34/58).

71. The United Nations, including all its programmes, funds and specialized agencies, should increase the awareness and expertise of its staff on the right to health of persons with disabilities in order to be able to cooperate more effectively with States from a human rights-based approach. The World Health Organization, as the leading agency in global public health, must include the rights and needs of persons with disabilities in all its lines of work and operations and ensure that the health of persons with disabilities is addressed comprehensively and from a rights perspective, always in close consultation with representative organizations of persons with disabilities.

VI. Conclusions and recommendations

72. **Persons with disabilities have the right to the highest attainable standard of health without discrimination. However, in practice they experience poorer**

access to health care and poorer health outcomes than the general population owing to several structural factors, such as stigma and stereotypes, discriminatory legislation and policies, barriers to accessing primary and secondary care, limited availability of disability-specific services and programmes, poverty and social exclusion. Furthermore, persons with disabilities face serious human rights violations in health-care settings, including denial of treatment; non-respect of their free and informed consent; different forms of exploitation, violence and abuse; and forced sterilization, forced contraception and other violations of their sexual and reproductive health and rights.

73. Mainstreaming the rights and needs of persons with disabilities in health care is crucial to end this situation of inequality. While disability-specific services and programmes are needed to address some of the particular needs of persons with disabilities that cannot be met by making general health care programmes inclusive, as a general rule all health-care services and programmes must be inclusive of and accessible to persons with disabilities. In the framework of the 2030 Agenda for Sustainable Development, States should conduct a review of their national health-care systems with a view to achieving universal health coverage as a way to increase the access of persons with disabilities to health care, particularly primary care services.

74. The Special Rapporteur makes the following recommendations to States with the aim of assisting them in realizing the right to the highest attainable standard of health of persons with disabilities:

(a) Recognize by law the right of persons with disabilities to the highest attainable standard of health and remove all legal barriers that prevent them from accessing health and health-care-related information, goods and services, including legislation that discriminates against them in the provision of health insurance;

(b) Conduct a comprehensive legislative review process to abolish or revoke all laws and regulations that infringe on the autonomy of persons with disabilities receiving health care, including legislation that allows coercion in health-care settings;

(c) Implement inclusive health-care systems that mainstream the rights and needs of persons with disabilities in all health services and programmes, including primary care; and ensure access to specific services and programmes for disability-related needs;

(d) Take appropriate steps to achieve universal health coverage for persons with disabilities and ensure that health-care services and programmes are available, accessible, adequate and affordable for all persons with disabilities;

(e) Guarantee that health-care services and programmes include a human rights-based approach to disability, are non-discriminatory, seek informed consent prior to any medical treatment, respect privacy and are free from torture or other cruel, inhuman or degrading treatment;

(f) Design and implement health literacy programmes and activities that are inclusive of and accessible for persons with disabilities;

(g) Promote early identification and intervention strategies and provide support to families of children with disabilities, including through information, education and services, to increase their understanding and capacities to address the health needs of their children without stigma or discrimination;

(h) Design awareness-raising campaigns and training programmes for health-care professionals to change their perceptions regarding persons with disabilities, and provide guidance on how to render adequate age-, gender- and disability-sensitive services;

(i) Ensure effective and independent monitoring of all public and private health-care facilities and programmes that provide services to persons with disabilities to prevent all forms of exploitation, violence and abuse;

(j) Actively involve and consult with persons with disabilities and their representative organizations in all decision-making processes related to the implementation of health and health-care-related legislation, policies and programmes;

(k) Collect appropriate information, including statistical and research data disaggregated by sex, age and disability, on the health status and the access to health care of persons with disabilities;

(l) Mobilize resources in the framework of the Sustainable Development Goals to increase the access of persons with disabilities to health care, ensuring that all investments are inclusive of them, and refrain from adopting any retrogressive measures that directly or indirectly affects persons with disabilities.

75. **The Special Rapporteur also recommends that the World Health Organization and the rest of the United Nations system adequately consider the right of persons with disabilities to the highest attainable standard of health in all their work and operations, in close consultation with representative organizations of persons with disabilities, including when assisting States in achieving universal health-care coverage and in the implementation of the Sustainable Development Goals.**

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Item 74 (b) of the preliminary list*
Promotion and protection of human rights: human rights questions, including alternative approaches for improving the effective enjoyment of human rights and fundamental freedoms

Human rights to safe drinking water and sanitation

Note by the Secretariat

The Secretary-General has the honour to transmit to the General Assembly the report of the Special Rapporteur on the human rights to safe drinking water and sanitation, Léo Heller, submitted pursuant to Assembly resolution 64/292 and Human Rights Council resolution 33/10.

* A/73/50.

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Report of the Special Rapporteur on the human rights to safe drinking water and sanitation

Summary

The Special Rapporteur on the human rights to safe drinking water and sanitation, Léo Heller, submits the present report on the principle of accountability in the context of the realization of the human rights to water and sanitation pursuant to Human Rights Council resolution 33/10. He analyses in the report the concept of accountability on the basis of three dimensions: roles, responsibility and standard; providing explanations and justification; and compliance through enforcement. He also provides guidance and examples of how rights holders can hold States and other relevant actors to account for ensuring the enjoyment of the human rights to water and sanitation and for their actions, inaction and decisions that affect the realization of those rights.

I. Introduction

1. Pursuant to Human Rights Council resolution 33/10, the Special Rapporteur on the human rights to safe drinking water and sanitation, Léo Heller, was mandated to identify challenges and obstacles to the full realization of those rights, as well as protection gaps, good practices and enabling factors. In the present report, he has focused on the principle of accountability in the context of the realization of human rights to water and sanitation and aimed to clarify the concept of accountability and the implications for the human rights to water and sanitation. He has sought to provide guidance and examples of how rights holders may hold States and other accountable actors to account for ensuring the enjoyment of the human rights to water and sanitation and for their actions and decisions that affect the realization of those rights.

2. In order to consult various stakeholders, the Special Rapporteur sent questionnaires to States and other stakeholders, which elicited a total of 28 submissions. [1] In addition, he convened a brainstorming round table on 13 September 2017 and an expert consultation on 14 and 15 May 2018. Finally, he consulted the general public and other stakeholders with a series of questions through social media sites throughout June 2018.[2]

A. Why accountability?

3. Different actors in the water and sanitation sector have explored the concept of accountability and aimed to formulate how the concept might be applied to the specificities of the sector.[3] However, there is no widely understood or agreed definition of the concept, in particular in the context of the realization of the human rights to water and sanitation. Therefore, clarification of the concept is essential for that sector, which involves a variety of actors related to the realization of those rights, including government entities (i.e. central and local governments and regulators), international organizations, transnational and national corporations and non-governmental organizations (NGOs).

4. Furthermore, globalization and the neoliberal wave have weakened the role of the State in the provision and regulation of water and sanitation services, and the imbalance of power has at times affected the exercise of the human rights to water and sanitation. This raises questions as to the effective regulation of private service providers and, in turn, poses challenges to accountability mechanisms, especially considering that those services are provided through a system of natural monopoly, with usually only one provider for a given territory. Another unique feature of the water and sanitation sector is the widespread presence of informal service providers that are not regulated and operate without a licence and that, as a result, may not be held accountable. Similarly, in the context of a crisis, there exists no clear

[1] See http://www.ohchr.org/EN/Issues/WaterAndSanitation/SRWater/Pages/PrincipleOfAccountability.aspx.

[2] www.twitter.com/srwatsan and www.facebook.com/srwatsan.

[3] See, among other references, Office of the United Nations High Commissioner for Human Rights (OHCHR) and Centre for Economic and Social Rights, *Who will be accountable? Human Rights and the Post-2015 Development Agenda* (Geneva, OHCHR; Brooklyn, New York, Centre for Economic and Social Rights, 2013); United Nations Development Programme (UNDP) Water Governance Facility/United Nations Children's Fund (UNICEF), *Accountability in WASH: Explaining the Concept* (2015); End Water Poverty and others, *Global Review of National Accountability Mechanisms for SDG 6* (London, 2018); and Benjamin Mason Meier and Yuna Kim, "Human rights accountability through treaty bodies: examining human rights treaty monitoring for water and sanitation", *Duke Journal of Comparative & International Law*, vol. 26, No. 1 (November 2015).

accountability framework based on human rights to provide guidance and standards, which, combined with the urgency of the situation in which actors operate, creates a gap where no one is held accountable.

B. Conceptualizing accountability

5. The concept of accountability is multifaceted. From an evaluative approach, "accountability" is seen as a broad value covering other values and goals, such as good governance, democracy, participation, transparency, equity, efficiency, integrity and responsibility.[4] In a broader sense, accountability is used to qualify a state of affairs or the performance of an actor. It is related to "responsiveness" and to a "sense of responsibility", that is, a willingness to act in a transparent, fair and equitable way.[5] From an analytical approach, accountability is described as involving the "justification of an actor's performance vis-à-vis others, the assessment or judgment of that performance against certain standards, and the imposition of consequences", if the actors fail to meet applicable standards.[6]

6. Accountability is a core human rights principle and is often considered together with the right of access to an effective remedy and with international and national mechanisms that provide redress to victims for human rights violations. In the context of transitional justice, accountability is discussed in conjunction with monitoring, truth-seeking, justice and reconciliation. Accountability is also explained as "the means by which individuals and communities take ownership of their rights and ensure that States, as primary duty-bearers, respect, protect and fulfil their international and national obligations".[7]

7. The essence of both the principle of accountability and human rights is about balancing power in order to protect the most marginalized and those living in the most vulnerable situations. The principle of accountability aims to mediate the relationship between people as rights holders and, in particular, those that wield power and affect the enjoyment of the former's rights by exercising State-like powers or decisive and asymmetrical power that has considerable potential impact on people.[8] In this sense, accountability may be characterized as having two main functions: a corrective function, addressing individual or collective grievances and sanctions for wrongdoing; and a preventive function, clarifying aspects of policy or service delivery as good practices, and aspects that need to be adjusted to apply the principle of accountability effectively.[9]

8. Another aspect of accountability is the empowerment of rights holders to request information and actions to be taken so that they may scrutinize the policies and practices of States and other actors and to have them make necessary changes. This requires spaces for participation, transparency, access to information, monitoring,

[4] Mark Bovens, "Two concepts of accountability: accountability as a virtue and as a mechanism", *West European Politics*, vol. 33, No. 5 (2010).

[5] Mark Bovens, "Public accountability: a framework for the analysis and assessment of accountability arrangements in the public domain", 2005.

[6] Jutta Brunnée, "International legal accountability through the lens of the law of State responsibility", *Netherlands Yearbook of International Law*, vol. 36, No. 1 (December 2005).

[7] Catarina de Albuquerque and Virgina Roaf, *On the Right Track: Good Practices in Realising the Rights to Water and Sanitation* (Lisbon, 2012).

[8] Arne Vandenbogaerde, *Towards shared accountability in international human rights law: Law, Procedures and Principles*, vol. 7, *Law and Cosmopolitan Values* (Mortsel, Belgium, Intersentia, 2016).

[9] OHCHR and Centre for Economic and Social Rights, *Who will be accountable? Human Rights and the Post-2015 Development Agenda*, p. ix.

assessment and oversight of progress or possible setbacks in the realization of the rights, as well as enforcement mechanisms.

9. Several types of mechanisms support the effective implementation of the various dimensions of accountability. Some mechanisms include institutionalized oversight structures and performance assessments designed to ensure horizontal accountability within organizations or institutions, allowing the imposition of binding or non-binding judgments, sanctions and recommendations. Accountability is also implemented vertically, through bodies with judicial or corrective powers, to which rights holders have access for claiming their rights and enabling the remediation of any adverse effect of non-compliance with human rights. Another vertical mechanism is the special procedures of the Human Rights Council: the mandate holders receive complaints from affected individuals, irrespective of the exhaustion of local remedies, and can directly address States and other actors by sending letters of allegations requesting information on the alleged violation and future actions. Accountability mechanisms therefore exist at both the national and international levels. For the purpose of the present report, the Special Rapporteur has focused on mechanisms readily available for individuals at the national level and, where relevant, briefly referred to international and regional mechanisms.

10. In view of the various elements of the principle of accountability, the Special Rapporteur has explored the concept through a three-dimensional approach: actors involved in the provision and regulation of water and sanitation services must have clearly defined responsibilities and performance standards (sect. II); actors must provide explanations for and justification of their actions, inaction and decisions to affected populations, which implies access to information in a transparent manner and spaces for interaction between actors and affected people (sect. III); and mechanisms should be in place to oversee and ensure actors' compliance with established standards, impose sanctions and ensure that corrective and remedial action is taken (sect. IV).[10]

II. Who is accountable, who can hold actors accountable and for what?

11. The principle of accountability requires that actors have clearly defined roles, responsibilities and performance standards.[11] These actors are those in a position of authority who can positively or negatively influence the realization of the human rights to water and sanitation through their actions, inaction or decisions. The adequate application of this principle involves clearly defining who is accountable, who can hold actors accountable, and what actors must be accountable for.

A. Actors in the accountability framework

1. Who is accountable and to whom

12. States are accountable to the population in their territory, irrespective of their residential or legal status in that territory, and to those that are affected by the cross-border activities of the State. However, actors involved in water and sanitation service provision or whose conduct may affect the enjoyment of the rights to water and sanitation are not limited to States. As a result of their de facto participation in water and sanitation services, actors other than State may be held accountable for their

[10] Ibid., p. 10.

[11] UNDP Water Governance Facility/UNICEF, *Accountability in WASH: Explaining the Concept*, p. 10.

conduct, in particular when they affect the realization of the human rights to water and sanitation through their influence, decisions, actions or inaction. While in the current report the Special Rapporteur has adhered to the fundamental relationship between actors grounded in international human rights law, which imposes human rights obligations upon States, he has also identified how individuals may directly hold other actors accountable. This follows the rights-based approach, which takes into account the duties of a full range of actors beyond States, including individuals, local organizations, private companies, funders and international institutions.

13. Actors other than States that are accountable in the water and sanitation sector include formal and informal service providers, which range from private companies, NGOs and community-based organizations to individuals involved in service provision. They also include business enterprises that may have an impact on the enjoyment of the human rights to water and sanitation in the course of their operation. Public or private companies may positively influence the development of infrastructure and increase access to public services. However, they can also commit serious human rights abuses or be complicit in their violation. Examples include disconnections when users are incapable of paying, water pollution, over-abstraction and forced displacement of populations owing to megaprojects that affect proper access to water and sanitation services. Bilateral and multilateral funders can also impose a type of service provision or tariff schemes through a series of conditions or funding criteria, with an impact on the enjoyment of human rights, in particular with respect to the affordability of services (see A/72/127). In the present report, those entities are referred to as "other accountable actors", that is, actors other than State that are involved in or affect, through their decisions and actions, the provision of water and sanitation services to individuals and communities.

14. Other accountable actors face multiple accountability demands that are sometimes challenging. For example, NGOs need to report to their donors, and a continuation of funding depends on positive programme results (upward accountability). They also need to be answerable to the people whom they provide services to and to adjust their programmes when necessary (downward accountability). At times, it may be uncertain to what extent NGOs are exercising accountability towards their donors rather than towards the people whom they represent. In addition, regulators are at the interface between policymakers, service providers and users, with corresponding accountability demands. Private companies are accountable to their shareholders, the users of the services that they provide and the people whom their actions affect, which may lead to tensions in terms of which interests should be pursued.

2. Who can hold actors accountable

15. In the framework of the human rights to water and sanitation, rights holders are the legitimate individuals entitled to hold actors accountable for affecting the enjoyment of their rights. Individuals can hold actors accountable directly or delegate that role to members of civil society or other entities (vertical accountability). For example, human rights bodies, including national human rights institutions and ombudspersons, are mandated to seek justice for grievances expressed by rights holders. Individuals can also voice their concerns through civil society networks and user associations.

16. In addition to individual rights holders, other accountable holders such as a State actor with formal authority may request explanations or impose penalties (horizontal accountability). For example, regulators oversee service providers' compliance with the standards of the human rights to water and sanitation and are granted the power to enforce existing regulations so as to ensure the enjoyment of those rights by users (see A/HRC/36/45).

17. Relations among actors in the accountability framework are also influenced by the type of institution mandated to ensure accountability. A national human rights institution may hold a local municipality accountable for a violation or omission relating to the rights to water and sanitation, while international human rights mechanisms interact primarily with central Governments. At the international level, there are several processes that ensure that States and international monitoring bodies engage in an interactive manner, whereby the State is bound to provide information concerning its conduct and may face consequences if it fails to comply with its obligations under a given treaty. These bodies and processes include human rights treaty bodies that monitor the implementation of the core international human rights treaties, the universal periodic review of the human Rights Council, which is a peer-review mechanism that examines the implementation of human rights obligations, and the Compliance Committee under the Protocol on Water and Health, which aims to secure compliance with the obligations under the Protocol.

B. Allocation of roles and responsibilities

1. Governmental institutions

18. Within the governmental institutional framework, the roles and responsibilities related to the rights to water and sanitation are often fragmented among different ministries. In El Salvador, the management of water resources is performed by more than 20 bodies, including municipal authorities, rural water management boards and housing development agencies. Those bodies share the responsibility for distributing and supervising water resources (see A/HRC/33/49/Add.1, para. 25). In Egypt, the responsibility for drinking water and sanitation services straddled several institutions (see A/HRC/15/31/Add.3, para. 12, and A/HRC/15/31/Add.3/Corr.1). The fragmented allocation of roles and responsibilities results in a patchwork of ways by which States address the human rights framework, and it prevents individuals from holding States accountable for their human rights obligations effectively.

19. The responsibility is also shared between the central Government and subnational and autonomous governments. Central Governments generally hold primary responsibility for the planning, programming, regulation and financing of water and sanitation, while municipalities are primarily responsible for providing water and sanitation services to the population. For example, in Mongolia, each local administration is responsible for service provision to households, yet the Ministry of Food, Agriculture and Light Industry oversees the provision of water in pastoral land, in particular to the nomadic population that is dispersed throughout the country (see A/HRC/39/55/Add.2). In some countries, such as Portugal, a centralized State also includes autonomous governments, which have their own regulatory mechanisms and service provision (see A/HRC/36/45/Add.1).

20. The decentralization of service provision and fragmented responsibilities are a matter of concern when responsibilities are transferred from central Governments without a concomitant transfer of resources, knowledge, capacity and corresponding accountability mechanisms. Decentralization may also obscure national accountability mechanisms and hamper clarity as to who is accountable, when it is implemented without a clear allocation of roles and responsibilities. The Government of Spain reported that the decentralization of responsibility for water and sanitation services to the municipal level had resulted in significant heterogeneity, for example, with respect to how the quality control of services was ensured. Such heterogeneity

can be problematic for accountability when other controls or assessments are not planned for at the national level.[12]

21. Another challenge is related to the capacity of local governments. In South Africa, even though water and sanitation services are the competency of local governments, many municipalities, in particular in poor or rural areas, do not have the skills or capacity to implement their mandate.[13] This results in situations where funders bypass the accountability mechanism established by the Government and introduce separate monitoring and control systems,[14] thereby adding additional layers of complexity and making the identification of accountable actors more difficult.

22. As a result of fragmentation, decentralization and lack of coordination, unclear roles and responsibilities can make it difficult for people to know whom to turn to for assistance and whom to hold accountable for realizing their human rights to water and sanitation. In Tajikistan, while complaints may be filed online, by email and by calling emergency telephone numbers, finding out whom to call when users have problems with water and sanitation services seems to be a complicated process (see A/HRC/33/49/Add.2, para. 39).

23. Moreover, corruption flourishes in an environment where roles and responsibilities are unclear or shared among multiple institutions that can shift the responsibility onto one another for failures or non-compliance. Institutional fragmentation and complex funding arrangements, which are typical of the water and sanitation sector, make the sector vulnerable to mismanagement and corruption.[15]

2. Service providers

24. In the context of the provision of services, several elements challenge the identification of accountable actors. First, water and service provision relies on various models of provision ranging from direct services operated by the Government to delegated services operated by private or State-owned providers and small-scale providers without a mandate from the State, often providing challenges in identifying the accountable actor. In addition, there are countries where the water sector is organized into two main levels: first, the bulk level, which includes the activities of water abstraction, treatment and storage and wastewater transport and treatment; and second, the retail level, which covers the distribution of water supply to individual users and the collection of wastewater from users (the case of Portugal exemplifies this situation, see A/HRC/36/45/Add.1). Furthermore, large private service providers sometimes have complex hierarchal structures in place that may make the roles and responsibilities unclear or even not visible to the affected populations.

25. Another challenge related to service provision is the widespread informal provision or self-provision, which leads to situations where users are unable to seek assistance and to hold any actor accountable. For example, in Tuvalu, where freshwater supply mainly relies on rainwater, it is the responsibility of individuals and communities to collect and store rainwater and maintain rainwater tanks. In addition, it is not clear who is responsible for sanitation services, and individuals are often considered responsible for constructing and maintaining their own septic tanks (see A/HRC/24/44/Add.2, para. 9). Informal provision or self-provision is prevalent in areas hard to reach and where populations in vulnerable situations reside. Standards for services set up through regulation therefore only benefit areas that already benefit from formal services, leaving behind those in a more vulnerable situation. Informal

[12] Submission from Spain, answer to question 5 of the questionnaire.

[13] South African Human Rights Commission, *Report on the Right to Access Sufficient Water and Decent Sanitation in South Africa: 2014* (2014), p. 16.

[14] Water Integrity Network, *Water Integrity Outlook 2016* (Berlin, 2016), pp. 88 and 108.

[15] Ibid., p. 26.

service provision may be problematic in terms of accountability, as informal providers tend to be accountable to consumers only, on the basis of "availability" and price of services. This includes, for example, households supplied by privately managed water points, where water prices are prone to changes depending on scarcity and demand.[16] Informal providers also include organizations that provide free services, as this may dissuade recipients from speaking out when they receive unsatisfactory services, for fear of appearing ungrateful.[17]

26. The responsibility for service provision is sometimes passed on to communities, as observed in community-led total sanitation, a concept introduced to address open defecation in certain communities, urging people to install facilities themselves. The implementation of such an approach has been most effective where Governments have committed to accountability and capacity-building.[18] Moreover, the encouragement of using "shame" or "social stigmatization" as a tool for promoting behaviour change places the responsibility for making an entire area "open-defecation-free" on the community members. Alarmingly, this has led to stigmatizing practices and to extreme instances in which the investigation and punishment of acts of violence against people accused of defecating in the open have reportedly been denied, thereby violating the rights of those people to a remedy and related access to justice.[19] For example, the Clean India Mission is heavily target- and performance-oriented, with a time frame that is very short given the scale of its projected outcomes. Implementation involves intense competition at all levels. As an unintended consequence of the desire to obtain rewards, including the title "open-defecation-free", some aggressive and abusive practices seem to have emerged (see A/HRC/39/55/Add.1, para. 16). While the Special Rapporteur understands the value of placing communities at the centre of water and sanitation projects, he emphasizes that promoters of community-led total sanitation projects must ensure accountability for any human rights violations.

3. Development and humanitarian actors

27. Development cooperation in the water and sanitation sector involves various actors: the funder, the partner State and, when it exists, the implementing entity. The role of funders is significant, as their decisions may have an impact on the realization of the rights to water and sanitation in different ways, depending on the extent to which decisions are based on human rights standards and principles (see A/72/127). The role of implementing entities varies according to their specific role and responsibility, as well as to conditions established in the terms and conditions. In a development project, roles and responsibilities are often shared among those actors and it is often unclear whom to hold accountable, especially in the long term. The Paris Declaration on Aid Effectiveness and the Accra Agenda for Action use the phrase "mutual accountability" to describe the joint obligation that both the State and the development actor share in the development process. For this reason, it is important that projects involve the targeted community and be designed with a clear allocation of roles and responsibilities.

28. A similar challenge exists in the humanitarian sector, where a range of actors, from State and international organizations with different legal status to NGOs, are

[16] J. Koehler and others, "A cultural theory of drinking water risks, values and institutional change", *Global Environmental Change*, vol. 50 (May 2018).

[17] Submission from End Water Poverty in response to the questionnaire.

[18] UNICEF, Plan International and WaterAid, *Second Review of Community-led Total Sanitation in the East Asia and Pacific Region* (Bangkok, December 2015), p. ix.

[19] J. Bartram and others, "Commentary on community-led total sanitation and human rights: should the right to community-wide health be won at the cost of individual rights?", *Journal of Water and Health*, vol. 10, No. 4 (December 2012).

involved in the provision of water and sanitation services as part of their humanitarian assistance (see A/HRC/39/55). In situations of crisis, the roles and responsibilities of related actors — local government, humanitarian actors and development actors — are often unclear, with obscure delimitations of the point when those actors become accountable. In protracted situations, in particular, the boundaries between humanitarian and development interventions are often not clear, and the roles and responsibilities of those actors may therefore leave gaps or overlaps.

C. What are actors accountable for?

29. Affected populations can hold actors to account for failing to adhere to predetermined performance standards or to comply with human rights obligations. It is essential that the normative content of the human rights to water and sanitation and human rights principles be the fundamental basis for performance standards for all accountable actors.

30. First, the standards that actors are accountable for meeting are stipulated in legal and policy instruments by virtue of the State's incorporation of the framework of the human rights to water and sanitation into national laws, policy and regulation. The incorporation of those rights into the national legal and regulatory framework ensures the clarity of performance standards for actors involved in service provision and gives rights holders a legal basis for claiming their rights.

31. Several development actors have embedded the normative content of the human rights to water and sanitation in their policy framework and technical tools that provide guidance (see A/72/127). After analysing six case studies, the Special Rapporteur concluded that funders' policies constitute a heterogeneous patchwork. While some funders' policies consider the human rights framework, in particular the human rights to water and sanitation, others are only sporadically aligned with those rights and reveal varying degrees of clarity regarding their application to development cooperation.

32. Second, performance standards can be placed in a broad spectrum of contractual arrangements between Governments, which formally delegate service provision, and third parties. Similar to regulation, a contract is a proxy tool where the instrument delegating service provision defines the relationship between the public asset owner and the service provider and sets service standards (see A/HRC/36/45). With regard to the specific performance standard that the contractor is accountable for, it is important that contracts, which are normally valid for decades, offer the possibility to be reviewed and adapted over time. This allows States to implement their obligation to protect, directly or through regulatory bodies, and to hold service providers accountable. For example, in Portugal, the Court of Auditors released a report on public-private partnership municipal water services in which it concluded that the majority of concessions benefited the private sector to the detriment of municipal budgets and individual consumers (see A/HRC/36/45/Add.1, paras. 38–41).

33. Third, performance standards are found in internal policies of private service providers, in accordance with the Guiding Principles on Business and Human Rights, which outline that companies should integrate human rights commitments into their policies. An example is the code of ethics established by AquaFed, an international federation representing private water operators, which encourages its members to respect the human right to safe drinking water and to sanitation and to commit to a human rights policy, among others.[20] While not fully based on the human rights framework, some development organizations have developed instruments, for

[20] See www.aquafed.org/MediaAndPublications/CorporateDocuments.sls.

example the WASH Sustainability Charter, to reiterate their commitment to accountability.[21] Other organizations have made a clear commitment to accountability, such as WaterAid, which, in its global strategy for 2015–2020, indicates that it is accountable to those whose lives it hopes to see transformed, to those it works with and to those who support it.[22]

III. Providing explanations and justification

34. The principle of accountability requires States and other accountable actors to be "answerable" to affected population for their actions, inaction and decisions that have an impact on the enjoyment of the human rights to water and sanitation. Answerability refers to the requirement for actors to provide explanations and reasoned justification for their actions, inaction and decisions to the people affected by them, as well as the public at large. Actors can implement answerability in two ways: answering questions and providing information at the request of individuals; and providing information proactively, making the relevant information transparently available and creating open spaces for interactions with rights holders.

35. The first mode of applying answerability guarantees the right of individuals to hold States and other actors accountable by requesting explanations and information about issues ranging from levels and coverage of water and sanitation accessibility, tariffs, the quality of drinking water and environmental impacts to reasons for decisions on policies and programmes. Answers need to satisfy the requests for explanations and information in terms of clarity and timeliness. A genuine explanation requires the use of understandable and clear language and the dissemination of useful information. It also addresses the need for dialogue with rights holders and implies the possibility for the latter to object to the answers provided by the relevant actors. Furthermore, rights holders must be able to assess whether the justification is reasonable and to voice their opinions.

36. The second mode of implementing answerability is a proactive approach whereby States and other accountable actors make relevant information transparent and accessible. States have the obligation to give to individuals and groups full and equal access to information on water, water services and the environment, whether that information is held by public authorities or third parties (see Committee on Economic, Social and Cultural Rights, general comment No. 15 (2002) on the right to water, para. 48). In addition, in order to account for how they address their impact on human rights, business entities should be prepared to communicate that information externally, in particular when concerns are raised by or on behalf of affected rights holders (see A/HRC/17/31, paras. 18 and 21).

A. Enabling environment for answerability

1. Monitoring and reporting

37. Actors must provide reasoned justification and explanations for their conduct and decisions to those that they affect, which entails the establishment of mechanisms to collect and analyse relevant information through monitoring and reporting. As an enabling factor of answerability, States and other accountable actors must regularly monitor and report on actions and decisions that they take and provide the justification thereof.

[21] See https://washcharter.wordpress.com/charter/.

[22] See www.wateraid.org/uk/our-global-strategy.

38. Internal monitoring at the national level serves to show progress made in reducing the gaps among served areas, under the principle of progressive realization of human rights using the maximum resources available, as well as to track performance through periodic evaluation. It also involves a process of documenting human rights violations, so that information may be verified and used effectively.

39. Although monitoring human rights is predominantly the responsibility of the State, monitoring by other accountable actors can also provide an important perspective for creating an enabling environment for answerability. In order to identify, prevent, mitigate and account for how they address their adverse impacts on human rights, business enterprises should carry out human rights due diligence (Guiding Principles on Business and Human Rights, principle 17). Water and sanitation service providers and other institutions can set up internal systems to ensure an effective review of decisions and actions. Internal monitoring and evaluation structures may include approaches allowing service providers to assess and report on performance through dialogue with stakeholders. These internal tools and systems include annual reporting by private and public service providers on their planning, performance and spending.

40. Some mechanisms have been set up at the international level to monitor human rights obligations of State parties to a specific treaty. For example, treaty bodies such as the Committee on Economic, Social and Cultural Rights monitor the implementation by State parties of the right to water on the basis of the Committee's general comment No. 15. Other mechanisms oversee the implementation of political commitments, such as the World Health Organization/United Nations Children's Fund Joint Monitoring Programme for Water Supply and Sanitation and the voluntary national reviews of the high-level political forum on sustainable development, to monitor progress in the implementation of the sustainable development agenda. It has to be noted, however, that negotiations about accountability mechanisms at the time of developing the Sustainable Development Goals were tense and eventually led to the use of the phrase "follow-up and review" instead of "monitoring and accountability" in the outcome document.[23]

41. Yet, there are several challenges to proper monitoring and reporting. Whereas formal service providers, that is, those that usually provide access to piped water and sewerage, are able to collect data, informal service providers may not be forthcoming with data on service provision. Data received from formal service providers therefore do not present full and comprehensive information on progress in realizing rights, and this type of information alone is not adequate for States to explain and justify their policy decisions for the purpose of accountability. Support must be provided to small-scale and informal service providers to allow them to collect and provide reliable data about their services, so that accountability for the provision of services may also be extended to areas served by unregulated providers.

42. The collection, compilation and analysis of disaggregated data, as part of monitoring and reporting, are crucial to ensure the answerability dimension of accountability for the enjoyment of the rights to water and sanitation by marginalized groups and populations in vulnerable situations. States and other accountable actors must therefore adopt indicators that cover all the normative content of those rights and disaggregate them by prohibited grounds of discrimination.

[23] K. Donald and S.-A. Way, "Accountability for the Sustainable Development Goals: A Lost Opportunity?", *Ethics & International Affairs*, vol. 30, No. 2 (10 June 2016), p. 205.

2. Empowering individuals

43. The ability to exercise fundamental human rights is a key precondition for rights holders to hold actors to account by requesting information. Participation and access to information can both empower rights holders to influence or question decisions and to voice their needs, demanding accountability for their human rights. Freedom of expression fosters answerability, obliging policymakers to respond to their constituents so that lessons may be learned from past shortcomings and the delivery of services may be improved.[24]

44. Another precondition is removing barriers for individuals to exercise their demands. Individuals face several challenges when lodging complaints, including language and literacy barriers. Rights holders in many countries often indicate that it is easier to demand accountability from the government and other accountable actors at the local level than at the national level, for various reasons, including familiarity with local participatory platforms, travel costs and time spent.[25]

45. Activities initiated by civil society can empower people who have traditionally been excluded or marginalized to claim rights more effectively. Advocacy by civil society may itself generate accountability by increasing the pressure on States and other accountable actors to explain and justify their policies and actions.[26]

3. Combating corruption

46. In the context of answerability, access to information and transparency prevent corruption and can put pressure on government officials to be answerable. Corruption, on the other hand, restrains transparency, and accountability mechanisms can be seriously impeded when corruption blocks the sharing of reliable information among actors.

47. Another related aspect is protection from reprisals. Whistle-blower mechanisms must be in place at the level of government institutions and service providers so that corruption and violations of the rights to water and sanitation may be addressed. For example, in 2014, the mayor of Mexico City created an anti-corruption hotline for citizens and instituted whistle-blower protection.[27]

B. Ways to implement answerability

48. In order to implement answerability, spaces need to be created and mechanisms should be established for interaction between affected populations and States or other accountable actors, where decisions are explained, questioned and justified.

1. Access to information and participation

49. Individuals, by exercising their right to information, can demand of actors to justify their actions or decisions. For adequate implementation, the right to access to

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[24] OHCHR and Centre for Economic and Social Rights, *Who will be accountable? Human Rights and the Post-2015 Development Agenda*, p. 14.

[25] International Council on Human Rights Policy, *Local Rule: Decentralisation and Human Rights* (Versoix, Switzerland, 2002), pp. 19–22; and End Water Poverty and others, *Global Review of National Accountability Mechanisms for SDG6*.

[26] OHCHR and Centre for Economic and Social Rights, *Who will be accountable? Human Rights and the Post-2015 Development Agenda*, p. 44.

[27] Water Integrity Network, *Water Integrity Outlook 2016*, p. 155, quoting Citiscope, 2015 (see http://archive.citiscope.org/story/2015/mexico-citys-miguel-angel-mancera-cracks-down-corruption). See also Organization for Economic Cooperation and Development, *Integrity Review of Mexico: Taking a Stronger Stance Against Corruption* (Paris, 2017).

information must have a legal basis in national frameworks and should be guaranteed in regulations and contracts with service providers. Adequate resources should be allocated so that information may be made available to all, including through such special measures as translations and audio and sign language material. Laws and regulations must ensure both an effective and timely response to requests for information related to the rights to water and sanitation, and the dissemination of that information through easily accessible channels.

50. Information can be made available in several ways. In Zambia, the Southern Water and Sewerage Company implemented measures for measuring water usage by means of a mobile application, so that water bills are more transparent and less prone to tampering by corrupt staff members.[28] In Brazil, the NGO Article 19 developed a guide to encourage water and sanitation users to gain access to information mechanisms. The guide provides information on how citizens may participate and request information through, inter alia, public consultations, hearings and participatory committees.[29]

51. Participatory mechanisms can provide another venue to implement answerability (see A/69/213). States and other accountable actors should establish participatory mechanisms that allow individuals to express their concerns or become involved in discussions regarding policies and practices that influence access to water and sanitation. Those mechanisms should provide a genuine opportunity for raising concerns and be designed in a way that gives participants the power to influence decisions.

52. A specific example of participatory mechanism is physical public meetings. In Burkina Faso, television viewers are invited during a monthly show to enter into discussions with a minister or the president of the country on issues pertaining to water and sanitation, and the show combines online reporting and monitoring of progress with a live television audience to get feedback or clarification on progress or lack thereof.[30] Nepal offers another example, as local communities could engage in public meetings with service providers, asking them questions about tariffs and the lack of services and demanding answers. This resulted in many service providers taking the complaints of the residents into consideration and modifying their policies accordingly.[31] Other innovative mechanisms involve the use of information and communications technology. In the European Union, a new drinking water directive has recently been proposed, whereby information would have to be available online and via smart applications, which would allow for a systematic analysis of levels of implementation and achievements.[32]

53. However, many practical challenges still exist for people to participate meaningfully (see A/69/213). Even when the right to participation and the freedom to voice dissent formally exist in a country, people may not enjoy those rights in practice. In Mexico, for example, several community representatives, human rights defenders and civil society organizations informed the Special Rapporteur that they had experienced harassment, intimidation, threats or even arrest as a result of their

[28] See www.waterintegritynetwork.net/2017/11/30/swsc-promotes-integrity-zambia/.

[29] Article 19, *Guia Prático de Acesso à Informação em Agua e Saneamento* (Sao Paulo).

[30] Submission from End Water Poverty in response to the questionnaire.

[31] As communicated in a webinar of the Global Partnership for Social Accountability (see http://gpsaknowledge.org/events/what-is-the-role-of-citizens-in-demanding-the-delivery-of-equitable-water-services-wins-experience/#.WpQuGBPwbOS).

[32] European Commission, Proposal for a directive of the European Parliament and of the Council on the quality of water intended for human consumption (recast), COM(2017) 753 final 2017/0332(COD) (1 February 2018), p. 13, art. 14 and annex IV.

complaints or protests relating to access to water and the contamination of water sources (see A/HRC/36/45/Add.2, para. 62).

2. Complaint mechanisms

54. Complaint mechanisms are widely used as a tool to fulfil the answerability dimension of accountability, namely, requesting information, explanations and justification. Individuals can resort to the complaint mechanisms of their water and sanitation service provider when they would like to enquire about certain actions and decisions that have had an impact on their rights to access to water and sanitation services.

55. Actors that affect the enjoyment of the rights to water and sanitation through their conduct should make complaint mechanisms available to rights holders. Those actors include private entities affecting water quality or availability in a certain area, or NGOs that provide services or influence decision-making on water and sanitation projects. They must respond to rights holders' requests and concerns submitted through complaint mechanisms.

56. Governments can implement different complaint mechanisms within the framework of public participation. For example, in the development sector, the German international development agency GIZ works with integrity advisors, an external ombudsperson and a reporting system with compliance officers who may be contacted anonymously by all stakeholders involved, including the public, when rules have reportedly been breached by GIZ.

57. Effective complaint mechanisms may vary from online forms to local kiosks where people may submit a complaint verbally. In Tajikistan, the Governance, Advocacy and Leadership for Water, Sanitation and Hygiene programme implemented by the Water Governance Facility of the United Nations Development Programme and the Stockholm International Water Institute has supported the establishment of public advisory councils and, during dedicated meetings, complaints and requests from consumers are openly presented to the management of the water supply companies, which, in turn, provide explanations and commit to resolving issues.[33] Another example is Aguas de Comayagua, in Honduras, which has set up direct links to receive complaints and claims either in person or by telephone, as well as online and through social networks.[34]

58. Complaint mechanisms and other non-judicial human rights grievance mechanisms should meet the following principles to guarantee credibility and effectiveness: legitimacy, accessibility, predictability, equitability, rights compatibility and transparency.[35]

IV. Compliance through enforceability

59. The enforceability dimension of accountability encompasses two perspectives. First, it refers to a process whereby bodies and mechanisms oversee actors' compliance with standards that are in line with the normative content of the human rights to water and sanitation and human rights principles. In the event that the standards are not met, enforceability mechanisms impose sanctions and ensure that corrective and remedial actions are taken. Second, from the perspective of

[33] See www.watergovernance.org/programmes/goal-wash/tajikistan/.

[34] See servicioaguasdecomayagua.com/.

[35] See www.ohchr.org/EN/Issues/Business/Pages/ARP_II.aspx.

individuals, enforceability provides a venue to claim the rights to water and sanitation by enforcing actors' compliance and to exercise the right to an effective remedy.

A. Oversight as prerequisite of enforceability

60. As enforcement refers to the ability to oversee actors and apply sanctions when they give unsatisfactory answers, the oversight of actors' conduct to assess whether performance standards are met is a prerequisite to decisions on the application of sanctions.

61. Oversight mechanisms are set up within States — among the executive, the legislative and the judiciary — through the principle of separation of powers, whereby each institution holds the others to account on behalf of the people. Institutions are entrusted with a mandate to oversee other State agencies and private actors. Such institutions include regulators, human rights commissions and institutions, ombudspersons, anti-corruption agencies and State auditing institutions. Those bodies may be mandated to enforce public legal standards with strong fact-finding powers and determine remedies on their own initiative. Others may issue recommendations on corrective and remedial action. For example, the Colombian human rights institution Defensoría del Pueblo has published a study in which it reviewed progress on the realization of the rights to water and sanitation throughout the country and issued recommendations to the Government.[36]

62. At the national level, regulators play a key role in overseeing service providers' compliance with the normative content of the human rights to water and sanitation. As public bodies, regulatory actors are bound by States' international human rights obligations and must be able to collect, analyse and disseminate accurate information on compliance by service providers. In addition, national human rights institutions are mandated to oversee the implementation of and compliance with the human rights to water and sanitation, and civil society organizations also have an important role in verifying adherence to human rights standards by States and other accountable actors. Furthermore, media can play a major role in overseeing the actions of various actors in the water and sanitation sector. They can fulfil a watchdog function and rebalance power asymmetry, despite their lack of power to enforce any outcome of their oversight.

63. Social audits as oversight mechanisms can review official records and allow to determine whether State-reported expenditure reflects actual expenditure on the ground, and can be used as a tool to uncover corruption. An example is citizen report cards or similar mechanisms that allow users to grade the services that they receive. These mechanisms are also used to indicate perceived levels of corruption and for expenditure tracking exercises, social auditing and contract monitoring. Civil society can assess compliance with the human rights to water and sanitation by both State and private service providers. For example, the citizen observatory of public services Observatorio Ciudadano de Servicios Publicos, based in Guayaquil, Ecuador, promotes accountability among private service providers by monitoring whether their practices are in compliance with their contractual obligations and the law. In the event of suspected violations, they file complaints in a variety of forums while simultaneously publicizing them in the local news (see A/HRC/18/33/Add.1, para. 84).

64. With regard to development projects, in situations where the host State fails to provide adequate oversight, funders should improve the accountability of implementing

[36] Defensoría del Pueblo, *Acciones para el Impulso del Derecho Humano al Agua en Colombia: una Mirada al Sector de Agua Potable y Saneamiento Básico* (Bogotá, February 2014).

organizations by setting oversight as a criterion for projects. Funders should make funding less contingent on simplistic assessments of success and link it more closely to the criteria of capacity-building and learning.[37]

B. Enforceability mechanisms

65. There are various ways in which States and other accountable actors may be sanctioned for lack of compliance with their performance standards and individuals may request remedial or corrective actions. In addition to national judicial mechanisms that ensure execution of compliance by law, other non-judicial mechanisms at the national level can positively influence States and other accountable actors, such as media and consumer protection groups. The present report describes judicial and quasi-judicial mechanisms at the national level that individuals may resort to when they want to enforce certain actions or decisions related to their daily problems with water and sanitation services.

1. National judicial mechanisms

66. Although the judicial mechanism is often not the preferred way for rights holders, it is an important option for seeking redress when other mechanisms are exhausted. Not only can litigation serve to provide remedies to victims of violations of the rights to water and sanitation, but it also has the potential to serve the preventive function of accountability, prompt larger discussions on how those rights should be safeguarded in society and effect more transformative policy changes.[38] For this to happen, it is important that courts have the competence to assess cases related to violations of the human rights to water and sanitation and to allow public interest litigation and class actions.

67. Courts play a crucial role in ensuring that rights holders may hold actors other than States accountable for violations of their human rights to water and sanitation, in particular when relevant legislation is in place. In a case in Argentina, a court prohibited a private company from disconnecting the water supply because of non-payment, basing its ruling on article 11 of the International Covenant on Economic Social and Cultural Rights and other human rights instruments directly applicable in that country.[39]

68. Although there is a rise in the numbers of judgments on economic, social and cultural rights, in many jurisdictions some or even many judgments remain unimplemented.[40] In an attempt to ensure compliance, courts may retain supervisory jurisdiction over the enforcement of their rulings and recommendations. They may set up monitoring processes and require periodic reporting by Governments on steps taken to implement decisions. For example, in South Africa, after receiving a complaint about inaccessible toilets on a beach for persons with disabilities, a court ordered the local municipality to adjust the situation on the accessibility and acceptability of toilets within 30 days and to report to the South African Human Rights Commission within two months.[41]

[37] Ainoor Ebrahim, "Accountability In Practice: Mechanisms for NGOs", *World Development*, vol. 31, No. 5 (May 2003), p. 818.

[38] OHCHR and Centre for Economic and Social Rights, *Who will be accountable? Human Rights and the Post-2015 Development Agenda*, p. 40.

[39] Justice of the Peace (Moreno, Buenos Aires), *Usuarios y Consumidores en Defensa de sus Derechos Asociacion Civil v. Aguas del Gran Buenos Aires S.A.*, 21 August 2002.

[40] See https://www.escr-net.org/node/365113.

[41] South African Human Rights Commission, *Boogard vs Kouga Local Municipality, EC*, file reference number: EC/1415/2048, Report, 10 August 2016.

2. Quasi-judicial mechanisms

69. In addition to judicial mechanisms, quasi-judicial mechanisms are another forum for enforceability. Quasi-judicial mechanisms refer to an arbitrator or public administrative agency with the power to determine facts objectively and draw conclusions that will provide the basis for official action.

70. Complaint and dispute resolution mechanisms of international financial institutions may be used by individuals and communities that consider that they have been, or are likely to be, adversely affected by a project. The Special Rapporteur stresses that States represented on the boards of the World Bank and other development banks should make sure that their internal safeguards are guided by international human rights standards, including the human rights to water and sanitation. This would allow affected populations to seek effective remedies for projects that violate their rights.

71. Regulatory bodies provide another avenue to safeguard the process to submit complaints when the enjoyment of the rights to water and sanitation has been compromised. A growing number of independent regulatory bodies have established complaint mechanisms for the resolution of disputes between service providers and users (see A/HRC/36/45, para. 81). These bodies are often located at the local level and are therefore generally more easily accessible than courts. In the resolution of complaints against service providers, regulatory actors must ensure full disclosure of information on the proposed measures, reasonable notice of proposed actions, legal recourse and remedies for the individual affected and legal assistance for obtaining legal remedies (see Committee on Economic, Social and Cultural Rights, general comment No. 15, para. 56).

72. Regulators can use various mechanisms to enforce standards, including incentives, warnings, penalties for non-compliance (such as fines), denial of permits, issuing injunctions, increased inspections and the possibility of revoking contracts (see A/HRC/15/31, para. 52). For example, in Kenya, the Water Services Regulatory Board may recommend the removal of boards of directors and top management and ultimately withdraw licences.[42] However, it is a matter of concern that State governance structures can be weak and that regulators may lack the ability or means to ensure that rules are followed.

73. National human rights institutions can often receive complaints, investigate and recommend changes when systemic violations of the rights to water and sanitation are found. Scrutinizing the State's obligation to fulfil those rights, however, can be a challenge. In some cases, national human rights institutions have the mandate to address business-related grievances related to the rights to water and sanitation.[43] In the Plurinational State of Bolivia, the ombudsperson may handle complaints against private providers, including those of water and sanitation services. In case of an investigation, the ombudsperson issues recommendations and suggestions, and the authorities are required to inform him or her of the measures that they have taken to remedy the problem. Human rights institutions must have the capacity to monitor the rights to water and sanitation and to apply a coherent analytical framework when assessing the State's compliance with its obligation to fulfil those rights. In 2015, a manual was developed by the Asia-Pacific Forum of National Human Rights Institutions to strengthen the capacity of national human rights institutions to hold the

[42] Kenya, Water Act, 2002 No. 8 of 2002, Licence for Provision of Water Services, clause 10.3, para. 3.

[43] OHCHR, "Business and Human Rights: A Survey of NHRI Practices, Results from a Survey Distributed by the Office of the United Nations High Commissioner for Human Rights", 2008.

State and its institutions accountable for the fulfilment of the rights to water and sanitation.[44]

C. Enabling environment and challenges

74. Marginalized people and people in vulnerable situations often lack the capacity and opportunities to hold actors accountable for the failure to uphold the rights to water and sanitation or for violations and abuses of those rights. Enforceability mechanisms are mostly used by individuals who are already aware of such mechanisms and who can afford the costs and the time spent using them.

75. It is vital that rights holders be made aware that, when the complaint has not been resolved through the complaint mechanisms of their service provider, there are other opportunities that they can turn to immediately thereafter. Accountable actors should actively refer people to other mechanisms, including judicial and quasi-judicial mechanisms, if complaints cannot be resolved by the accountable actor. Ofwat, the economic regulator of the water sector in England and Wales, explains on its website that consumers that are not happy with the result of the complaint procedure may resort to their local Consumer Council for Water committee to investigate, and provides the relevant contact details.[45]

76. Furthermore, owing to the collective nature of the water and sanitation services, it is important that judicial and quasi-judicial bodies allow relevant cases to be brought before them by individuals, their representatives, third parties, NGOs, associations of trade unions or any other representative organizations. It is often easier for rights holders to voice their concerns and hold actors accountable collectively, for example through civil society organizations, consumer protection groups and water users organizations. In Kenya, for example, a case was submitted to the High Court with the support of Hakijamii, a human rights organization based in Nairobi, following a request by more than 1,000 individuals who had been evicted from their homes and, as a result, had suffered from lack of water and sanitation.[46] In Sweden, perfluoroalkyl and polyfluoroalkyl substances originating mainly from fire foam were found in drinking water. As a result, an NGO sued the private water supplier and claimed damages for the effects of those substances on the health of consumers.[47]

77. Strategies related to soft enforcement are also an important tool for obtaining formal enforcement. Human rights institutions, ombudspersons, NGOs and civil society organizations play a crucial role in ensuring compliance with judgments and recommendations, as they put pressure on Governments to provide remedies.[48]

78. Several remaining challenges need to be addressed. One challenge in ensuring the effectiveness of enforceability mechanisms is that, in some jurisdictions, human rights to water and sanitation are not justiciable, that is, not amenable to be

[44] Asia Pacific Forum of National Human Rights Institutions and the Center for Economic and Social Rights, *Defending Dignity: A Manual for National Human Rights Institutions on Monitoring Economic, Social and Cultural Rights* (Asia Pacific Forum of National Human Rights Institutions, Sydney; Center for Economic and Social Rights, Brooklyn, New York, January 2015).

[45] See https://www.ofwat.gov.uk/regulated-companies/investigations/ofwat-regulating-the-industry-monitoring-and-casework-whistleblowing-whistleblowing/.

[46] Kenya High Court, Constitutional Petition No. 2 of 2011 (Garissa), 23 June 2011.

[47] Submission from Sweden in response to the questionnaire.

[48] B. Cali and N. Bruch, *Monitoring the implementation of judgments of the European Court of Human Rights: A Handbook for Non-Governmental Organisations* (May 2011), p. 6. Examples include the International Network for Economic, Social and Cultural Rights (see https://www.escr-net.org/monitoring).

adjudicated in judicial or quasi-judicial forums. It is crucial that national laws provide a clear guarantee to individuals and groups who are potentially victims of a violation of their rights to water and sanitation, so that they may be able to file a complaint before a judicial body, request legal remedies and have those remedies enforced. Justiciability of the human rights to water and sanitation is an essential precondition for ensuring the effectiveness of judicial and quasi-judicial mechanisms as part of the enforceability dimension of accountability.

79. Another challenge is the lack of trust in available mechanisms. As observed in the report of the Special Rapporteur on his mission to Mexico, many individuals, especially those in vulnerable situations, do not trust the authorities, as many cases of violations of the human rights to water and sanitation do not reach tribunals, and substantive jurisprudence on those rights has been limited in comparison with other rights (see A/HRC/36/45/Add.2, para. 60). Attention must be paid to strengthening follow-up to rulings and ensuring the provision of remedies, so that violations and abuses do not go unpunished and trust may be restored.

80. Imposing certain sanctions, such as the withdrawal of licences, is challenging in a sector where there is often no alternative service provision, as the sanction may ultimately affect the users.[49] A solution for this was sought in Peru where a new law stipulates that service providers failing to attain a certain level of performance and good governance indicators fall under a transition regime, during which a separate institution controls the provider, which receives intensive support to facilitate a quick improvement of its performance.[50]

V. Conclusion and recommendations

81. **The principle of accountability is a core and a cross-cutting human rights principle. With the essential aim of balancing power to protect the most marginalized and those living in vulnerable situations, the principle of accountability can be used as a mechanism to hold States and actors other than States accountable for actions, inaction and decisions that affect the enjoyment of the human rights to water and sanitation. Similar to the concept of human rights, the concept of accountability is dynamic and evolving in nature, and requires a contextual analysis.**

82. **Accountability mechanisms in the water and sanitation sector exist at the local, national, regional and international levels. Some mechanisms may be directly accessible to affected populations, while others may require representatives to act on behalf of those populations. In the present report, the Special Rapporteur has focused on mechanisms that individual users may have direct access to for their everyday concerns related to water and sanitation services. The complexity of actors in the water and sanitation sector and its specificities imply that the traditional State-centred human rights framework leaves gaps in the existing accountability mechanisms. Furthermore, the Special Rapporteur has observed that accountability mechanisms often face challenges and that, in practice, they are often lacking altogether. As a result, when the rights to water and sanitation are affected, it is not always clear to whom related action may be attributed, why such action was taken, how sanctions may be enforced against those who caused harm or how to remedy the situation.**

[49] Submission from Germany in response to the questionnaire.

[50] Peru, Framework Law on the Management and Provision of Sanitation Services, as amended by Supreme Decree N° 008-2018-VIVIENDA of 18 May 2018.

83. **Consequently, the Special Rapporteur has identified the need to strengthen the three dimensions of accountability in the water and sanitation sector: roles, responsibility and performance standards; providing explanations and justification; and enforcement mechanisms for compliance. In order to establish an adequate accountability framework for affected populations, the Special Rapporteur has put forward one set of recommendations for States and another for all accountable actors, that is, States and other actors involved in the provision of water and sanitation services or whose actions, inaction and decisions affect access to water and sanitation services.**

84. **First, the adequate implementation of accountability requires a clear definition of who is accountable, who may hold actors accountable and what actors must be accountable for. Affected populations can hold States and other accountable actors to account for failing to adhere to predetermined performance standards or to comply with human rights obligations. Yet, the challenge lies in the difficulty of ascertaining who is accountable for access to water and sanitation services, particularly given the often complex architecture of governmental institutions in that sector, the involvement of private and informal service providers, the existence of regulators and situations where no one is identified as accountable.**

85. **For the first dimension on roles, responsibility and performance standards, the Special Rapporteur recommends that all accountable actors, including States, international organizations, bilateral and multilateral funders, non-governmental organizations (NGOs), private and informal services providers, independent regulators, transnational and national companies:**

(a) **Clearly identify the roles and responsibilities of entities whose influence, actions, inaction and decisions affect the provision of water and sanitation services, making those roles and responsibilities transparent and clear to the affected individuals;**

(b) **Ensure that resources, knowledge, capacity and corresponding accountability mechanisms are properly transferred when roles and responsibilities are transferred from one actor to another;**

(c) **Adopt the normative content of the human rights to water and sanitation and human rights principles as the fundamental basis for performance standards;**

(d) **Prioritize the provision of water and sanitation in line with the human rights to water and sanitation in situations of multiple accountability demands.**

86. **Specifically, States should:**

(a) **Establish clear coordination mechanisms within governmental institutions so that individuals do not need to resort to multiple actors in the Government to claim their rights;**

(b) **Strengthen the capacity of local governments and service providers to implement their mandates through a clear accountability process;**

(c) **Clearly allocate, define and attribute the responsibilities of all stakeholders involved in the water and sanitation sector in accordance with the framework on the human rights to water and sanitation, and regulate the implementation of those responsibilities;**

(d) **Identify informal service providers of water and sanitation services to individuals and communities and put in place regulations for those providers, making accountability mechanisms available;**

(e) When responsibilities for service provision are transferred to communities, ensure that accountability measures for any human rights violations that may occur owing to aggressive and abusive practices are in place.

87. Second, the provision of explanations and justification requires, on the one hand, that States and other accountable actors be able to answer questions and provide the information requested by individuals, in particular those marginalized and those in vulnerable situations who need to be empowered to request information and actively ask questions. On the other hand, States and other accountable actors should proactively and systematically provide information, in a transparent manner, as well as open spaces for interactions with affected populations. Both aspects rely on an effective and explicit human rights framework that upholds the right to information, participation, monitoring and reporting, in conjunction with advocating transparency and other principles to combat corruption.

88. For the second dimension of providing explanations and justification, the Special Rapporteur recommends that all accountable actors, including States, international organizations, bilateral and multilateral funders, NGOs, private and informal services providers, independent regulators, transnational and national companies:

(a) Regularly take note of and record actions and decisions taken and the justification thereof, including through setting up internal systems for an effective review of decisions and compliance with performance standards;

(b) Maintain clear and effective mechanisms to respond to requests and concerns from affected populations, giving timely answers to requests for information and explanations and ensuring clarity (by means of understandable and plain language) and that the information provided is useful;

(c) Facilitate the exchange of information in the form of dialogues or participation whereby affected populations may assess whether the information that they have received is reasonable, voice their opinions and be able to influence relevant decisions without language barriers;

(d) Regularly publish information on decision-making processes related to water and sanitation;

(e) Adopt indicators that cover all the normative content of the rights to water and sanitation and that are disaggregated by prohibited grounds of discrimination, while setting specific benchmarks in relation to each indicator.

89. Specifically, States should:

(a) Provide support to small-scale and informal service providers to allow them to monitor their own service provision;

(b) Legally guarantee the exercise of fundamental human rights, such as freedom of expression, right to information and participation, among others, which are a precondition for affected populations to hold actors accountable;

(c) Guarantee the process of complaint mechanisms in regulatory frameworks and concession contracts when provision is delegated.

90. Third, enforceability is critical to ensure the accountability of actors by imposing sanctions and remedial actions for violations and abuses by those actors. This is preceded by a process whereby bodies and mechanisms oversee actors' compliance with performance standards that are in line with the normative content of the human rights to water and sanitation. At the national level, judicial and quasi-judicial mechanisms serve as a means for affected

populations to hold States and other accountable actors to account. However, this needs to be complemented by an enabling environment that empowers the affected populations to lodge claims and that builds trust and effectiveness in the accountability mechanisms.

91. **With regard to the third dimension, namely, compliance through enforceability, the Special Rapporteur recommends that all accountable actors, including States, international organizations, bilateral and multilateral funders, NGOs, private and informal services providers, independent regulators, transnational and national companies:**

(a) **Establish an effective oversight system to trace the conduct of actors in the water and sanitation sector and to assess whether performance standards are met;**

(b) **Assess and address barriers faced by marginalized people and people in vulnerable situations to resort to a judicial or quasi-judicial mechanism, eliminating institutional, physical, economic, social or other barriers;**

(c) **Ensure that affected populations are made aware of the fact that, when complaints are not resolved through the mechanisms of their service provider, other enforcement mechanisms are available.**

92. **Specifically, States should:**

(a) **Ensure that all elements of the human rights to water and sanitation and human rights principles are included in the legal framework, so that the human rights to water and sanitation are justiciable and affected populations have a legal basis for their claims;**

(b) **Devise a mechanism that would enforce decisions on other accountable actors by interpreting national laws in a way that allows proceedings against those actors that are responsible for human rights violations and abuses.**